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Memory and Normal Ageing in Adults with Intellectual
Disabilities: A Research Portfolio

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Doctorate in Clinical Psychology

University of Edinburgh

April 2014

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TABLE OF CONTENTS

	<i>Page No.</i>
ACKNOWLEDGEMENTS	i
QUOTE	ii
ABSTRACT: THESIS PORTFOLIO	1
PART I: SYSTEMATIC REVIEW	3
CHAPTER 1: SYTEMATIC REVIEW JOURNAL ARTICLE	4
Abstract	5
1.1 Introduction	6
1.2 Aim	15
1.3 Method	16
1.4 Results	20
1.5 Discussion	40
1.6 References	48
CHAPTER 2: OVERVIEW	61
PART II: EMPIRICAL STUDY	62
CHAPTER 3: EMPIRICAL STUDY JOURNAL ARTICLE	63
Abstract	64
Introduction	66
Method	76
Results	83
Discussion	88
References	95

CHAPTER 4: EXTENDED METHODOLOGY	105
4.1 Design	105
4.2 Participants	109
4.3 Measures	113
4.4 Procedure	120
References	121
 APPENDICES	 126
Systematic Review	127
1. Research in Developmental Disabilities author guidelines	127
2. Search strategy	136
3. Quality criteria adapted from SIGN Guidelines	139
4. Summary of quality ratings of included papers	142
 Empirical Study	 143
5. Journal of Intellectual Disability Research author guidelines	143
6. Ethical approval: Scotland A Research Ethics Committee	146
7. Research & development approval: NHS Highland	148
8. Participant (easy-read) booklet	150
9. Participant information sheet	152
10. Staff information sheet	155
11. Participant consent form	157

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In dedication to my family and friends for their love and unwavering support.

'You have to begin to lose your memory, if only in bits and pieces, to realise that memory is what makes our lives.'

Life without memory is no life at all, just as an intelligence without the possibility of expression is not really an intelligence.

Our memory is our coherence, our reason, our feeling, even our action. Without it, we are nothing.'

(Buñuel, 1983, p.4¹)

¹ Buñuel, L. (1983). *My Last Sigh* (A. Israel, Trans.). New York: Knopf.

ABSTRACT: THESIS PORTFOLIO

Background: Assessment of dementia in adults with intellectual disabilities poses specific challenges. Firstly, there is a paucity of validated, standardised and appropriate neuropsychological assessments of memory for adults with intellectual disabilities. Secondly, there are difficulties determining whether performance on neuropsychological assessments are attributable to pre-existing intellectual disabilities, 'normal' ageing or part of a dementing process. A systematic review was therefore carried out to examine if there are memory changes associated with 'normal' ageing in the Down syndrome population. Following this an exploratory empirical research project was undertaken to examine one aspect of construct validity (i.e. convergent validity) of an associative memory test in a sample of adults with intellectual disabilities. This research project is presented as a journal article titled 'Convergent validity of the Visual Association Test (VAT) in adults with intellectual disabilities'.

Methods: 40 participants aged between 18-45 years were recruited from Community Learning Disability Teams. Participants completed the VAT and subtests of the modified Cambridge Cognitive Examination (CAMCOG-DS). IQ was assessed using the Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV). Correlational analysis of the test variables were carried out. Participants with a diagnosis of dementia were excluded from the study.

Results: All participants performed well on the VAT irrespective of age, gender or IQ. It was well received by participants. No significant correlations were found between the VAT and the subtests of the CAMCOG-DS or with

the subtests of the WAIS-IV. Therefore, there was no evidence of convergent validity with this test in this sample of participants.

Conclusions: While the VAT was found to be an easy, quick test to use with people with intellectual disabilities and all participants scored above 'floor' level, it was not found to have convergent validity with the CAMCOG-DS. Further research is needed to determine if the VAT represents a useful tool for assessment with this population.

Keywords: ageing, Down syndrome, intellectual disabilities, memory, neuropsychological tests, Visual Association Test.

PART I

SYSTEMATIC REVIEW

CHAPTER 1: SYSTEMATIC REVIEW

Memory changes associated with “normal” ageing in adults with Down syndrome: A systematic review

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Running head: MEMORY CHANGE WITH ‘NORMAL’ AGEING IN DS

*This review has been written in accordance with Research in Developmental Disabilities
(Appendix 1)*

Abstract: Systematic Review

Aim: This review aimed to advance our knowledge and understanding of memory changes associated with 'normal' ageing in adults with Down syndrome.

Methods: A literature search was conducted using various search engines including: MEDLINE, EMBASE, CINAHL, PsycINFO, ASSIA, Web of Science and Google Scholar, from the dates from which the databases began till July 2012. Inclusion and exclusion criteria are described. Quality of studies was assessed using the Scottish Intercollegiate Guidelines Network (SIGN) methodology checklist.

Results: The search identified eight studies. There were four longitudinal studies and four cross-sectional studies. There were some indications of changes in memory associated with 'normal' ageing. However, due to the significant methodological limitations, further research is needed to substantiate this.

Conclusion: There is a lack of rigorous empirical research examining memory associated with 'normal' ageing in adults with Down syndrome. Further research employing longitudinal designs are essential in order to evidence the 'normal' trajectory of memory abilities with age in this population.

Keywords: ageing, Down syndrome, intellectual disability, memory, neuropsychological assessment.

1.1 Introduction

It is well acknowledged that adults with Down syndrome (DS) are more likely to develop Alzheimer's disease (AD) than the general adult population, and at a much earlier age (British Psychological Society & Royal College of Psychiatrists, 2009). Over the last 30 years, there has been an increasing amount of research on the assessment and presentation of AD in the DS population (see Prasher, 2005). The neuropsychological assessment of AD in the DS population in particular, poses great challenges in comparison to its assessment in the general adult population (see Section 1.13 for review of these difficulties). These difficulties often mean that longitudinal administrations of assessment are generally required. Additionally, other conditions have been identified which mimic the symptoms of AD, for example, depression, thyroid dysfunction, and vision and hearing problems (e.g. Oliver, Crayton, Holland, & Hall, 2000; Prasher, 1999; Walker, Dosen, Buitelaar, & Janzing, 2011). These and other possible causes of symptoms must be fully considered in order to accurately assess and clinically diagnose AD in this population.

In the general adult population, there is a reasonable understanding of the hypothesised cognitive continuum of 'normal' ageing, mild-cognitive impairment (MCI) and 'pathological' ageing, such as AD (Portet et al., 2006).

This increased knowledge has improved the clinical diagnosis of the latter two conditions. Research is only just beginning to examine this continuum in the DS population. For example, a research project is currently underway to examine whether the clinical concept of MCI can be diagnosed in this population (Krinsky-McHale, 2013) which may or may not lead to AD. In the past 20 years, research has also begun to investigate the changes in cognitive functioning which occurs in the 'normal' ageing process in people with DS (see Zigman et al., 2008). 'Normal' ageing is characterised by a decline in memory and other cognitive abilities which are typically expected as people age. For instance, episodic, prospective and working memory begin to show slight changes around twenty years of age with further decline over time in the general adult population (e.g. Brickman et al., 2009; Nilsson, 2003).

Distinguishing between AD and 'normal' ageing is important for assessment, clinical diagnosis and intervention purposes. In the general population, 'normal' ageing provides the baseline from which a clinical diagnosis of MCI or AD is made (Grundman et al., 2004). It is important therefore to understand what 'normal' ageing represents in the DS population. This would allow clinicians to establish whether any clinically observed deterioration in cognitive functioning is indicative of 'normal' ageing or AD as well as improving the likelihood of early diagnosis. This systematic

review will review the research on memory changes associated with 'normal' ageing. Prior to this, the literature relevant to this systematic review will be outlined.

1.1.1 Alzheimer's disease

Alzheimer's disease (AD) is the most common form of dementia which is characterised by a progressive loss of memory, deterioration in at least one other cognitive function (e.g. executive function) and reduced capacity for tasks of everyday living (American Psychiatric Association, 1994). In 2010, there was an estimated 35.6 million people with dementia worldwide. This is expected to increase exponentially to an estimated 65.7 million by 2030 and to 115.4 million by 2050 (Prince et al., 2013). The mortality rates vary across studies but research has reported that following a diagnosis at age 60-70 the median mortality rate is approximately 6-10 years, by age 70-80 this reduces to 3 years and in the 90s to 2 years (Brookmeyer, Corrada & Curriero, 2002; Rait et al., 2010). Death typically results from other health issues such as circulatory and more commonly, respiratory system diseases (e.g. Brunnstrom & Englund, 2009).

1.1.2 Alzheimer's disease in Down syndrome (DS)

Down Syndrome (DS) is the most common genetic cause of intellectual disability, affecting about one in every 1000 live births in the UK (Down Syndrome Association, 2012; Sherman, Allen, Bean, & Freeman, 2007). Historically, people with DS did not survive past childhood. In 1929, the life expectancy of people with DS was nine years of age (Penrose, 1949). In recent years, with the advances in medical treatment and with deinstitutionalisation, increasing numbers of people with DS are reaching 60 years of age and beyond (Bittles & Glasson, 2004; Torr, Strydom, Patti, & Jokinen, 2010).

The association between DS and AD has been well documented (see Prasher, 2005). Historically, it was believed that all people with DS eventually develop the condition, as DS is caused by a superfluous copy of chromosome 21 which is implicated in development of AD (Webb & Murphy, 2012). Additionally, post-mortem studies showed that at the age of 40 years, the majority of people with DS exhibit the neuropathological indicators of AD (Mann, Yates, & Marcyniuk, 1984; Wisniewski, Wisniewski, & Wen, 1985). In particular, the widespread formation of neuritic plaques and neurofibrillary tangles in the brain. However, more recent studies have revealed that not all people with DS demonstrate the clinical characteristics of the disease (e.g.

Coppus et al., 2006; Krinsky-McHale, Devenny, Kittler, & Silverman, 2008).

This implies that although there is an association between the neuropathology of AD and DS, as yet, the exact relationship between them is not completely known. It also suggests that AD is not inevitable in all adults with DS (Prasher, 2005). Prevalence rates of dementia are comparable to the general population, but occur 30-40 years earlier in people with DS (Holland, Hon, Huppert, & Watson, 1998).

1.1.3 Neuropsychological assessment of Alzheimer's disease in DS

Neuropsychological assessment has a significant role to play in the assessment and diagnosis of AD (Scottish Intercollegiate Guidelines Network [SIGN], 2006; National Institute for Health and Clinical Excellence [NICE], 2006). However, assessing for AD in people with DS is particularly challenging. The variability in their intelligence poses challenges in interpreting performance on single neuropsychological assessments (e.g. Crayton, Oliver, Holland, Bradbury, & Hall, 1998). Their performance may be within the cut-off points suggestive of cognitive deterioration associated with AD, however, their score may be a reflection of their pre-existing intellectual disability (ID) not a cognitive deterioration. For this reason, longitudinal administration of tests is recommended (Burt & Aylward, 2000). This however, is not without its difficulties. Standardised

neuropsychological assessments that have been adapted from the normal adult population often result in 'floor' effects (Crayton et al., 1998). This means that people often score zero or obtain the lowest scores on the test due to their ID. As a consequence, the tests are unable to determine a deterioration in function (e.g. Stanton & Coetzee, 2004). As a result of these challenges, it was believed that testing people with pre-existing cognitive impairments concealed the diagnosis of AD dementia in people with DS (see reviews by Nieuwenhuis-Mark, 2009; Zigman & Lott, 2007). Despite these difficulties with assessments there has been an abundance of research examining the cognitive changes associated with AD in people with DS (e.g. Devenny, Krinsky-McHale, Sersen, & Silverman, 2000; Margallo-Lana et al., 2007; Oliver et al., 1998). However, with time assessments have been adapted, developed and improved (Silverman et al., 2004) taking into account the above difficulties.

1.1.4 Cognitive decline in the general population with 'normal' ageing

In the general population, there is a gradual decline in memory as people age 'normally' with different memory systems exhibiting differential susceptibility to ageing (reviewed by Brickman & Stern, 2009). Broadly, the most stable memory systems across the life span appear to be: perceptual, procedural (i.e. practiced habit procedures), and semantic (i.e. general

knowledge about the world) (e.g. Craik, 1998; Nilsson, 2003). Systems that show decline are episodic (i.e. specific events) and working memory (i.e. information held and manipulated) (e.g. Luo & Craik, 2008; Nyberg, Backman, Erngrund, Olofsson, & Nilsson, 1996). From around the age of 20 years of age there is an almost linear age-related decline in episodic and working memory (see Salthouse, 2010 for review).

Performance on episodic tasks that show changes with 'normal' ageing are those that involve free recall of information (i.e. when people have been given no cues to help them to retrieve information) (e.g. La Voie & Light, 1994) and tasks that ask people to retrieve the context or source of an event (e.g. Cansino, 2009; Spencer & Raz, 1995). Tasks of prospective memory which involves asking people to carry out a future act without a prompt (e.g. Henry, McLeod, Phillips, & Crawford, 2004) also demonstrate decline. Additionally, performance that requires people to change information in their mind without help, namely working memory tasks, show declines with 'normal' ageing (Craik & Jennings, 1992). Evidence has shown that working memory mediates decline in other memory systems and cognitive functions (Brickman & Stern, 2009).

There is variability in memory performance in the trajectory of 'normal' ageing. As a result, researchers have examined the risk factors that may influence memory, such as cardiovascular risk factors and 'cognitive reserve' (see Brickman & Stern, 2009).

It is important to note that studies which have examined ageing may have included participants with dementia which may confound the 'normal' ageing evidence base (Crayton et al., 1998). Additionally, changes in performance, particularly in episodic memory, have employed cross-sectional designs which may overestimate the changes over time (Nilsson, 2003).

Standardised norms for different neuropsychological tests provide the most valuable information on age trends in cognitive functioning (see Salthouse, 2010). Additionally, standardised norms of different tests acknowledge that various cognitive functions are influenced by age. For example, the Rivermead Behavioural Memory Test, 3rd edition (RBMT3, Wilson et al., 2008), examines verbal, visual, spatial, prospective memory and new learning. This test demonstrates that a raw score of 10 on the immediate recall of a story (i.e. free recall) will have a scaled score of: 10 for people aged 16-24 years; 11 for people aged 45-54 years; and 13 for people aged 75-89

years. Therefore, as people age, free recall of verbal information decreases. Tests also provide 'normal' ageing norms and provide cut-offs for 'pathological' ageing (e.g. ACE-R, Mioshi et al., 2006). Hence, these norms set the baseline from which 'pathological ageing' is identified.

1.1.5 Rationale for the current review

Given the evidence that the general adult population show memory changes associated with 'normal' ageing and the known difficulties with differentiating between AD, pre-clinical AD and 'normal' ageing in DS (Ball et al., 2006), it is important to review what we know of 'normal' ageing in the DS population. A clearer understanding of this area should aid clinicians with their diagnosis of memory (and other cognitive) difficulties, and also identify further areas of research.

1.2 Aim

This review will address the following question with the aim of advancing our knowledge and understanding of potential changes in memory associated with 'normal' ageing in adults with DS. This review will consider:

Question: Are there memory changes associated with 'normal' ageing in adults with DS? What types of memory show changes and at what age do these occur?

1.3 Methods

1.3.1 Inclusion and exclusion criteria

The framework **PCOS** (population; comparators; outcomes; study design) described by the Centre for Reviews and Dissemination guidelines (CRD, 2008) was used to guide the selection of studies for inclusion and exclusion in this review. This is an internationally recognised framework commonly used in systematic reviews (Needleman, 2003). Only articles available in the English language were included.

1.3.2 Population

Studies were included in the review if their main aim was to assess cognitive changes associated with 'normal' ageing and if at least half of the participants included adults (aged over 18) with a diagnosis of Down syndrome (DS). Studies were excluded if their primary focus was on examining the cognitive changes associated with dementia. That is, studies that included participants with a diagnosis of dementia were excluded. Articles that aimed to validate a neuropsychological test of memory were also excluded.

1.3.3 Comparators

Memory was the area of interest explored in the review. Studies with a comparison or control group of participants with intellectual disabilities (ID) (other than DS) were included.

1.3.4 Outcome measures

Memory was the main outcome measure. Only studies which used standardised neuropsychological assessments to assess memory were included in the study.

1.3.5 Study design

The Scottish Intercollegiate Guidelines Network (SIGN, 2012) was used to assess the quality of studies. SIGN is recognised as one of the most robust scoring systems for assessing the quality of evidence (Schünemann, Fretheim, & Oxman, 2006). It is an original member of the Guidelines International Network and aims to meet the standards of the AGREE (Appraisal of Guidelines, Research and Evaluation) Instrument. This is an internationally recognised review system (SIGN, 2012).

Case-series and case reports studies were excluded due to the risk of bias in these articles. Additionally studies with no objective data, in particular,

literature reviews, systematic reviews, unpublished dissertations and book reviews, were also excluded.

1.3.6 Search strategy and identification of relevant literature

In order to ensure that the review had not already been completed previously the following were searched: The Cochrane Library database of Cochrane Database of Systematic Reviews (Cochrane Reviews); Cochrane Central Register of Controlled Trials (Trials); National Institute of Health and Clinical Excellence (NICE); and the SIGN guidelines (see Appendix 2, Table 1). No reviews were found which addressed the aim of this review.

Following this a wide range of databases were searched to identify relevant literature (see Appendix 2, Table 1). In order to provide a comprehensive review, databases were searched from the year they began till July 2012. These included: the OVID databases: EMBASE (1974 - July 2012) and MEDLINE(R) (1946 - July 2012); EBSCO databases: PsycINFO (1987 – July 2012); CINAHL (1981 – July 2012); and Applied Social Sciences Index and Abstract (ASSIA) (1987-July 2012). Reference lists from relevant studies of frequently cited articles were examined further to ensure that all studies had been identified. This was completed using the Web of Science database and the general search engine Google and Google Scholar (Appendix 2, Table 2).

A combination of free text key word searches and subject headings were used to identify relevant articles. The main search terms were ageing, neuropsychological tests and Down syndrome. A variety of search terms were used for each of these terms and then combined with **OR** (Appendix 2, Table 1). The titles and abstracts of studies were read to ascertain whether the whole article was relevant to be included in the review prior to excluding studies. Whole articles were retrieved if this was unclear.

1.3.7 Quality assessment of included studies

The methodological quality of the included studies were examined by adapting the “Methodology Checklist 3: Cohort Studies” (SIGN, 2001-2012). As the focus of this review is concerned with changes associated with ageing, longitudinal studies were considered to be more robust (Christensen, 2001) and therefore studies included were separated by design and then ranked by quality criteria. Quality criteria are described below in Table 3 (see Appendix 3) with the maximum total score awarded being 28 points.

Each article was assessed by the first author and an independent reviewer. If consensus was not achieved, this was discussed and the study in question was assessed by a third rater prior to a final decision being made.

1.4 Results

In total, 216 articles were identified by the systematic search of the literature. The titles were screened initially to eliminate irrelevant articles (N=41). These were articles that examined aging in relation to physical health, such as menopause or gait development or in terms of neuro-anatomy, rather than in relation to cognitive functioning. 175 articles remained. Of these, the titles and abstracts were then examined and articles were excluded that did not meet the primary inclusion criteria. These were articles which examined: changes in cognitive functioning associated with dementia; neuroanatomy; the effectiveness of medication; review articles; articles which examined the effects of dementia on caregivers; epidemiology; neuropsychology in relation to dementia and diagnosing Alzheimer's disease. If it was unclear whether an article met the inclusion or exclusion criteria on the basis of the title and abstract, it was examined as a full text article. As a result, 65 articles remained. The full texts of these potentially relevant citations were retrieved and all PCOS criteria were then used systematically to assess for eligibility. Eight articles met the criteria for inclusion in the current review. Further details of the search strategy are presented in Figure 1.

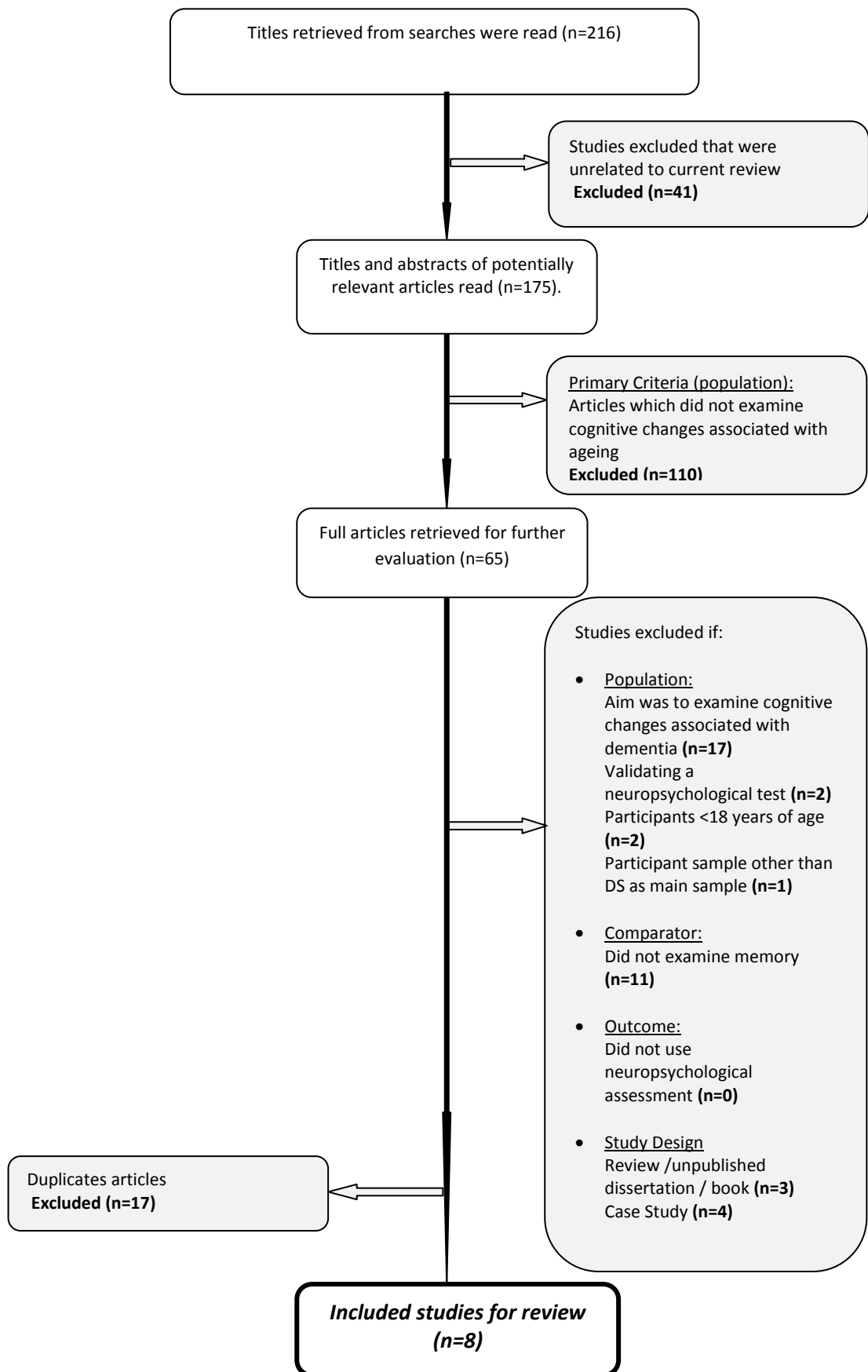


Figure 1. Process of excluding articles for current review.

Table 4 summarises: (a) design; (b) participant numbers; (c) IQ assessment; (d) neuropsychological measures used; (e) memory changes; (f) reported effect size; and (g) quality ratings awarded to each included article. The table is ordered in terms of the quality rating of each article with better quality studies at the top of each section. The first part of the table displays longitudinal designs and the second half displays cross-sectional.

Quality ratings were not categorised into an overall category rating (i.e. good or poor) as it was thought that this would be highly subjective. Longitudinal studies scored lower in terms of their quality (8-13 points) to cross-sectional studies (13-20 points). Nevertheless, as mentioned previously longitudinal studies were considered more robust for this type of review. Therefore, they were given more weight in terms of their findings than the cross-sectional studies and will be considered separately. For a detailed itemisation and summary of each individual quality rating (not including design), see, Table 5 (Appendix 4).

Table 4. Summary of included studies

Author / year	Design	Down syndrome group	Comparison group	Period	Down syndrome age range	IQ	Measures	Dementia assessed Y/N	Changes	Effect size Y/N	Rated
Carr (2003)	Longitudinal	N=37 (only 29 able to complete memory tests)	None	5 years (Followed up from 6 weeks of age.)	Study examined memory at 30 and 35 years.	BPVS; Leiter	OCDB; RBMT-C	Yes	Decline in visual memory significant decline. However, suspected 'dementing' process. Most memory scores showed a subtle decline (i.e. episodic memory).	No	13/28
Carr (2012)	Longitudinal	N=23	None	15 yrs (Followed up from 6 weeks of age)	Study examined 30-45 years	BPVS; Leiter	OCDB; RBMT-C	Yes	Significant decline in RBMT-C (6 individual items and total score). However, suspected 'dementing' process. Cohort showed minor decline on most memory subtests (i.e. episodic and prospective memory).	No	13/28

Author / year	Design	Down syndrome group	Comparison group	Period	Down syndrome age range	IQ	Measures	Dementia assessed Y/N	Changes	Effect size Y/N	Rated
Devenny et al. (1996)	Longitudinal	N=91 30-39yrs (n=22); 40-49yrs (n=42); >50yrs (n=27)	ID (n=64) 30-39yrs (12); 40-49yrs (n=24); >50yrs (n=28)	6 yrs	31-63 years	IQ gathered from clinical notes. Not specified which assessment used.	IBR; SRT; ViMT.	Considered	Older participants with DS poorer performance on free recall (episodic memory) than younger participants than DS. Processing speed reduced with age.	No	10/28
Devenny et al. (1992)	Longitudinal	N=28 <35 Yrs (n=12) >35 yrs (n=16)	ID (n=18) ID <35 (n=5) >35 (n=13)	3-5 yrs	27-57 years	IQ gathered from clinical notes. Not specified which assessment used.	BMT; EMS; ViMT	Yes	No significant age related decline in memory.	No	9/28
Das, Divis et al. (1995a)	Cross-sectional	N= 29 40-49yrs (n=16); 50-62years (n=13)	ID (n=31) 40-49yrs (n=16); 50-62 yrs (n=15)	N/A	40-62 years	IQ gathered from clinical notes: WAIS, WAIS-R / SBR IQ	CAS; DRS; MAT; PPVT-R;	Yes	No changes in memory. No Figure memory too difficult for all groups (i.e. 'floor').	No	20/28

Author / year	Design	Down syndrome group	Comparison group	Period	Down syndrome age range	IQ	Measures	Dementia assessed Y/N	Changes	Effect size Y/N	Rated
Das & Mishra (1995b)	Cross-sectional	N=11 26-40yrs (n=3); 41-50yrs (n=4); 51-60yrs (n=4);	ID (n=28) 26-40yrs (n=10); 41-50yrs (n=10); 51-60yrs (n=8)	N/A	26 to over 50 years of age.	PPVT-R	CAS	No	No significant age related decline in memory.	No	17/28
Krinsky-McHale et al. (2003)	Cross-sectional	N=48	ID (n=46)	N/A	Mean age (43.65) no range noted.	IQ gathered from clinical notes. Not specified which assessment.	PFCT	Considered	No age associated decline in implicit memory.	Yes	16/28
Caltagirone et al. (1990)	Cross-sectional	N=20 <35years (n=9); >35 years (n=11)	ID (n=20) AD (n=15)	N/A	Mean range: Young (28 years); Old (39.5 years) No range noted.	PM	BNT; VeMT; PM; Copy of Drawings	No	Young DS lower mean scores in verbal memory than Mixed ID (not sig.) Sig. Difference between Old DS and AD group in verbal memory test. No noted differences with age.	No	13/28

Abbreviations: AD: Alzheimer's disease; BPVS: British Picture Vocabulary Test; BMT: Buschke Memory Test; BNT: Boston Naming Test; CAS: Cognitive Assessment (Das-Naglieri); DS: Down syndrome; DRS: Dementia Rating Scale; EMS: Evaluation of Mental Status; IBR: Evaluation of Mental Status; ID: Intellectual disabilities; MAT: Matrix Analogies Test; PM: Progressive Matrices; OCDB: Oliver and Crayton Dementia Battery; PM: Program Matrices; PPVT-R: Peabody Picture Vocabulary Test, Revised; Picture Fragment Completion Task; RBMT-C: Rivermead Behavioural Memory Test-Children's Version; SRT: Selective Reminding Test; SBR: Stanford-Binet Ration IQ; VeMT: Verbal Memory Test; ViMT: Visual Memory Test; WAIS: Wechsler Adult Intelligence Scale; WAIS-R: Wechsler Adult Intelligence Scale, Revised.

1.4.1 General characteristics of included studies

Two studies were carried out in the UK (Carr, 2003, 2012), one in Italy (Caltagirone, Nocentini, & Vicari, 1990), three in America (Devenny, Hill, Patxot, & Wisniewski, 1992; Devenny et al., 1996; Krinsky-McHale et al., 2003; Devenny, Zimmeril, Kittler, & Silverman, 2002) and two in Canada (Das & Mishra, 1995b; Das, Divis, Alexander, Parrila, & Naglierii, 1995a). Four articles employed a longitudinal design to examine a total of 171 participants with DS (Carr, 2003, 2012; Devenny et al., 1992, 1996). Four articles employed a cross-sectional design to examine a total of 108 participants with DS (Caltagirone et al., 1990; Das et al., 1995a; 1995b; Krinsky-McHale et al., 2003). The observation periods for the longitudinal designs ranged from 3 years (Devenny et al., 1992) to 15 years (Carr, 2012).

1.4.2 Participant characteristics

The size of the sample of people with DS ranged from 11 (Das et al., 1995b) to 91 (Devenny et al., 1996). Their ages ranged from 30 years (Carr, 2003, 2012) to 69 years (Das et al., 1995b). Two articles did not report the age range of their sample and reported the means instead (Caltagirone, 1990; Krinsky-McHale et al., 2003).

Recruitment of participants in studies involved purposive sampling from day centres (Caltagirone et al., 1990), public services (Das et al., 1995a) and the community (Carr, 2003, 2012; Das et al., 1995b; Devenny et al., 1992, 1996; Krinsky-McHale et al., 2003).

Sampling criteria in the form of inclusion and exclusion criteria were reported for six of the studies for the participants and comparison groups (Caltagirone et al., 1990; Carr, 2003, 2012; Devenny et al., 1992, 1996; Krinsky-McHale et al., 2003). The inclusion criteria were mainly: no history of seizures, no evidence of a dementing process, no severe sensory or motor impairment (Caltagirone et al., 1990; Devenny et al., 1992; 1996); and IQ over 35 (Devenny et al., 1992, 1996). Devenny et al. (1992) specified that participants had to be over 25 years of age and Devenny et al. (1996) included participants 30 years of age and over. Carr (2003, 2012) accepted all babies with DS born during one year in one geographical area and did not report any other criteria for inclusion. They used this as their sample to follow longitudinally but only examined memory functioning from the age of 30 years. Two studies did not report inclusion or exclusion criteria (Das et al., 1995a, 1995b).

1.4.3 Assessment of IQ

Three studies did not assess for intelligence in their sample (Devenny et al., 1992, 1996; Krinsky-McHale et al., 2003). Instead IQ was obtained from examining the clinical records of their participants and recording the results of their most recent assessment. The type of assessment employed to calculate the Full Scale IQ was not documented in the published research studies.

Four articles assessed for IQ in their study. A range of tests were used including: British Picture Vocabulary Scale (BPVS; Dunn et al., 1982) and the Leiter International Performance Scale (Leiter, 1980) (Carr 2003, 2012); Peabody Picture Vocabulary Test-Revised (PPVT; Dun and Dun, 1981) (Das et al., 1995b); and Progressive Matrices'47 (Raven, 1949) (Caltagirone et al., 1990). The final study (Das et al., 1995a) reported the use of assessments available in clinical files (i.e. Wechsler Adult Intelligence Scale or Stanford Binet ratio IQ) but also carried out further assessment as part of their study namely the PPVT-R and Matrix Analogies Test-Expanded Form (MAT; Naglieri, 1985).

Participants varied in their Full Scale IQ. One article reported the range of IQ in their sample (41-77 in <35 year group and 45-64 in >35 year group)

(Devenny et al., 1992). Most articles reported the mean IQ (Carr, 2003, 2012; Das et al., 1995a, 1995b; Devenny et al., 1992, 1996; Krinsky-McHale et al., 2003) which ranged from 41.3 to 55.8 across studies. Caltagirone et al. (1990) did not report on the IQ level in their sample.

In summary, a variety of measures were used to assess for IQ in the included studies which created difficulties when attempting to generalise the data. Additionally, a few studies took IQ scores from clinical files but failed to report on the measure used. This also creates difficulty when comparing findings.

1.4.4 Comparison groups

Six articles included a comparison group of participants with intellectual disabilities of different aetiologies (Caltagirone et al., 1990; Das et al., 1995a, 1995b; Devenny et al., 1992, 1996; Krinsky-McHale et al., 2003). Caltagirone et al. (1990) also included a group of participants with intellectual disabilities of different aetiologies who were, on the basis of neuropsychological tests, considered to be suffering from Alzheimer's disease. Two articles did not include a comparison group (Carr, 2003, 2012), however, the authors had followed up their sample from 30 years of age to 45 years of age.

Of the six studies that used comparison groups, five reported on the age of their sample. For three of the studies (Das et al., 1995a; Devenny et al., 1992; Krinsky-McHale et al., 2003), the DS groups were found to be younger than the ID group. Das et al. (1995a) reported that the young DS group was 3.69 years younger than the young ID group, and the old DS group was 2.13 years younger than the old ID group. Devenny et al. (1992) reported that the young DS group was 0.7 years younger than the young ID group and the old DS group were 2.3 years younger than the old ID group. Krinsky-McHale et al. (2003) reported that the mean age of their DS group was 10 years younger than the ID group. For one of the studies (Caltagirone et al., 1990) the DS group was found to be older than the ID group by 9.3 years. Devenny et al. (1996) reported that with their 30-39 year group, the DS group were older by one year; in the 40-49 age group, they were matched for age and in the over 50 group the ID group were 6 years older than the DS group. Das et al. (1995b) did not report the mean or median of their sample so the appropriateness of their matching could not be reported.

In terms of IQ, the six studies which had comparison groups varied in their matching of groups (Caltagirone et al., 1990; Das et al., 1995a, 1995b; Devenny et al., 1992, 1996; Krinsky-McHale et al., 2003). Four studies reported IQ ranges, with mean IQ scores ranging from 51.46-59.07 (Krinsky-

McHale et al., 2003; Das et al., 1995a; Devenny et al., 1992, 1996). One study (Das et al., 1995b) reported on mean mental age determined by PPVT-R scores. There was a difference of one year and nine months between their DS and ID comparison samples. However, the difference was not significant according to the authors. Nevertheless, Das et al. (1995a) found lower mean IQ scores for the DS groups than their corresponding ID groups (differences of 8.56 IQ points and 1.65 IQ points for the young adult and old adult groups). The authors reported that the matching was not 'completely satisfactory'.

Four studies did not assess for IQ in their samples but gathered information from clinical files (Caltagirone et al., 1990; Devenny et al., 1992; 1996; Krinsky-McHale et al., 2003). The assessment used was not reported, therefore, it is difficult to ascertain whether the groups were well matched. There was a mean difference of 7.61 IQ points difference between the ID and DS group (with ID groups being higher) in Krinsky-McHale et al.'s study (2003). Devenny et al. (1992) found a difference of 3.9 IQ points difference between DS and ID in the under 35 age group, and a difference of 0.5 IQ points in the over 35 age group. Devenny et al. (1996) reported differences of 13 IQ points in the 30-39 age group, five IQ points in the 40-49 age group and seven IQ points in the over 50s age group. All of the differences were in the

direction of higher scores in ID groups than DS groups. Caltagirone et al. (1990) did not report on the IQ level in their comparison samples.

1.4.5 What types of memory have been examined?

Four studies assessed episodic memory (Caltagirone et al., 1990; Devenny et al., 1992, 1996; Krinsky-McHale et al., 2003), typically tests of verbal memory (Caltagirone et al., 1990; Devenny et al., 1992, 1996). Tests of visual memory were also included in two studies (Devenny et al., 1992, 1996). One study examined implicit memory (Krinsky-McHale et al., 2003).

Four studies used batteries of neuropsychological assessments, which included tests of memory (Carr, 2003, 2012; Das et al., 1995a, 1995b). Batteries of assessments such as the Rivermead Behavioural Memory Test-Children's Version (RBMT) and Oliver and Crayton Dementia Battery (OCDB) were used in two studies (Carr, 2003, 2012). Within these batteries different aspects of memory were assessed for using the following subtests such as: name learning, remembering, picture memory, story recall, faces, route, message and memory for sentences. Two studies used the Das-Naglieri Cognitive assessment system (Das et al., 1995a, 1995b). This battery includes tests of visual and verbal memory and attention and planning.

1.4.6 Have other cognitive functions been examined?

Three studies examined changes in IQ with age (Carr, 2003, 2012; Das et al., 1995a). The longitudinal data showed small but insignificant declines in IQ were evident with ageing from 30 to 35 years (Carr, 2003). However, in their longitudinal study, Carr (2012) found that IQ remains relatively stable until the age of 45 years. However, Carr (2012) only assessed participants up until the age of 45 years. Whilst, Das et al. (1995a) in a cross-sectional study found that IQ showed signs of decline after the age of 50 years.

Three studies (Das et al., 1995a, 1995b; Devenny et al., 1996) also examined other cognitive functions. Two studies reported differences between older people with DS and younger people with DS on tests of planning and attention (Das et al., 1995a, 1995b) such that people over the age of 40 perform poorer than those under the age of 40 years. One study of longitudinal design considered that older people are poorer at tasks involving speed of motor processing (Devenny et al., 1996), suggesting processing speed declines with age in people with DS. Although there are some differences noted with age in terms of cognitive abilities other than memory, there is not enough evidence to make conclusions as only three papers tested other cognitive functions and these were limited in range.

1.4.7 Screening and assessing for dementia

Three studies (Devenny et al., 1992, 1996; Krinsky-McHale et al., 2003) made some effort to screen for dementia prior to enrolment to the studies. A variety of methods were used, including screening for a history of functional loss in the clinical notes and by way of informal discussion with care workers (Devenny et al., 1992, 1996). One study did not screen but specified the exclusion of participants with a diagnosis of dementia or that exhibited significant declines on the memory measures employed in their study (Krinsky-McHale et al., 2003). Three studies did not attempt to screen or exclude participants for dementia (Caltagirone et al., 1990; Das et al., 1995a, 1995b). Screening for dementia prior to enrolment in the research was not relevant for Carr (2003, 2012) as they recruited at 6 weeks of age.

Dementia was also screened for during the research process. Of the eight studies, four studies included an assessment to help to distinguish 'normal' ageing from 'pathological' ageing, specifically dementia (Carr, 2003, 2012; Das et al., 1995a; Devenny et al., 1996). Carr (2012) confirmed or suspected dementia for eight participants in their study. These participants showed significant declines on the RBMT-C (20-39 points) and showed large declines on the OCDB (16-25 points). The authors did not report how the diagnosis was made, for example diagnostic criteria or multidisciplinary assessment. In

comparison, Devenny et al.'s (1996) study described the assessment of dementia including multidisciplinary assessment, diagnostic criteria (i.e. DSM-III-R) and discussion with regard to conditions that may have mimicked the symptoms. They found that four of their 91 participants showed changes associated with AD. They also reported that the four participants demonstrated personality changes, a progressive decline in cognitive performance and these affected their daily living skills. Das et al.'s (1995a) study used the Dementia Rating Scale (DRS) which demonstrated significant decline in the older DS group. The authors discussed this as 'ageing' but it was unclear whether the change was due to AD rather than 'normal' ageing. They also reported that careful medical screening should be carried out in future research but did not report on their employment of this in their study.

In those suspected of dementia, seven of the studies did not assess or screen for conditions which may have produced cognitive impairment, such as depression or thyroid dysfunction. Only Devenny et al.'s (1996) study, assessed for depression, anxiety and thyroid dysfunction in the individuals suspected of AD.

1.4.8 Systematic review question: *Are there memory changes associated with 'normal' ageing in adults with DS? What types of memory show changes and at what age do these occur?*

Based on the results from the four longitudinal studies (Carr, 2003, 2012; Devenny et al., 1992, 1996), there appears to be some changes in memory as adults with DS increase in years (Carr, 2003, 2012; Devenny et al., 1996). However, these changes were not statistically significant.

A small deterioration has been noted as early as 35 years in people with DS in terms of verbal and visual recall and in immediate and delayed memory tasks (i.e. episodic memory) and memory for remembering a route (i.e. spatial memory) (Carr, 2003). These slight deteriorations continue up to 45 years of age (Carr, 2012) with subtle changes in prospective memory noted. As this study only included participants up to the age of 45 years, changes beyond these were not studied. However, Devenny et al. (1996) found that older participants over 50 years of age with DS show poorer performance on episodic memory tasks of free recall compared with younger people with DS (i.e. age group 30-39 years and age group 40-49 years).

Devenny et al.'s (1992) longitudinal study found no age-associated changes in visual memory and no deterioration in test scores over a 3-5 year period. Although this study included participants with DS up to 55 years of age, given this short time period of assessment, it is unlikely that the authors would have found changes. However, Devenny et al.'s (1996)'s study over a six year period, confirmed these finding by reporting no evidence of decline in short-term visual memory ability in adults up to the age of 63 years of age.

The cross-sectional studies reported no age-associated changes in verbal, implicit memory or visual memory (Das et al., 1995a, 1995b; Caltagirone et al., 1990; Krinsky-McHale et al., 2003). Das et al. (1995a; 1995b) studies examined participants from 26-62 years age range. The other two studies did not report on the age range in their studies but reported on the mean instead. In this case, the mean was 28 years for the younger group and 39.5 years for the older group (Caltagirone et al., 1990) with an overall mean of 43.65 years (Krinsky-McHale et al., 2003). In terms of the comparison groups, one study was not well matched for IQ (Das et al., 1995a) one did not report the IQ level in their comparison sample (Caltagirone et al., 1990) and one had higher IQ in the ID group, but this was not significant (Krinsky-McHale et al., 2003). Hence, this may have influenced the results. While appropriate tests were employed, the authors only tested one type of memory. For example, only

implicit (Krinsky-McHale et al., 2003) verbal (Caltagirone et al., 1990) and visual (Das et al., 1995a, 1995b) memory were examined. Additionally, the sample sizes within the studies were relatively small (ranging from 11-48 participants), therefore, it is unlikely that any differences in memory ability would have been demonstrated.

Overall, one longitudinal study and four cross-sectional studies did not report any memory changes associated with ageing, however, due to their limitations it is difficult to draw conclusions. As previously discussed, longitudinal research is more suited to ageing research, therefore those studies were deemed more robust.

Based on these results only, there appear to be some evidence for subtle changes in memory associated with 'normal' ageing in people with DS. There were slight episodic memory and spatial memory changes which began around age 35 years of age then changes in prospective memory from 45 years of age were noted.

1.5 Discussion

1.5.1 Summary of the evidence

The research literature examining memory changes associated with 'normal' ageing is sparse in comparison to the literature base examining Alzheimer's disease (AD) in the Down syndrome (DS) population (see Lott, 1982; Zigman, Silverman, & Wisniewski, 1996, for reviews). Of the studies included in this review, three studies noted subtle changes in episodic, spatial and prospective memory associated with 'normal' ageing (Carr, 2003, 2012; Devenny et al., 1996) whilst the other five studies did not. The three studies that did show changes were considered more robust due to their longitudinal design. Therefore, from the literature, it appears that there may be subtle changes in episodic, spatial and prospective memory which are consistent with the cognitive changes associated with ageing in the general adult population (see Kausler, 1994; Newman & Kasniak, 2000). However, given the limited range of memory abilities tested it is unclear whether there are changes in other types of memory as people with DS age 'normally'. Evidence from the general population has suggested that there are also changes in working memory (e.g. Luo & Craik, 2008; Nyberg et al., 1996).

In terms of determining at what age people demonstrate memory changes, it is not clear given the lack of studies available for review and of those that were reviewed five did not demonstrate any changes in memory. Of the studies that demonstrated changes, two followed their samples from 30-45 years of age and noted subtle changes age in episodic, spatial and prospective memory at 35 years of age which continued up until 45 years of age (Carr, 2003, 2012). The third study demonstrated that people with DS over 50 years of age showed poorer performance on episodic memory tasks of free recall compared with younger people with DS (Devenny et al., 1996). Four of the five studies that did not find any changes may have been due to their cross-sectional design and limited samples which may have reduced their ability to demonstrate any differences between groups. Furthermore, only one study reported an effect size, however, this may have been due to the restricted samples available.

Overall, this review has not been able to fully establish whether there are memory changes, which memory abilities change and when these changes take place with 'normal' ageing in people with DS. Furthermore, there are several methodological limitations which may have influenced the findings.

1.5.2 Methodological limitations

There are significant methodological limitations apparent in the reviewed studies. Of the limited studies available for review, there has been difficulty synthesising the data due to the inherent differences in the: type of neuropsychological tests employed; age range of samples; IQ range; and sample size of participants. This heterogeneity has reduced the review's ability to make meaningful comparisons.

The majority of studies did not employ neuropsychological tests with robust psychometric properties. As mentioned previously, there is a lack of memory tests available for use with people with DS (Crayton et al., 1998). Additionally, the psychometric properties of memory tests have yet to be established as there is a lack of normative data available for the DS population.

There was limited assessment of other cognitive functions in the reviewed studies. Memory abilities cannot be clearly understood without comprehensive assessment of other abilities. For example, it has been shown that executive functioning can impact on memory performance (Salthouse, Atkinson & Berish, 2003). Of the studies that examined other cognitive functions, an adequate range of assessments were not conducted.

None of the studies explicitly stated how they differentiated between cognitive changes associated with 'normal' ageing and 'pathological' ageing. Only one study reported clearly on their assessment and diagnosis of AD (i.e. employing the DSM-III-R guidelines). However, Aylward et al. (1997) working group suggested that the ICD-10 framework should be used to diagnose dementia in people with DS as it also emphasises non-cognitive changes associated with the disease. None of the other studies reported using classification systems to diagnose AD. Research has shown that the type of classification system used to diagnose dementia will significantly affect the prevalence rates of AD in research and clinical populations (Burt et al., 1998). Hence, it is difficult to ascertain whether the memory changes noted are in fact a 'normal' ageing process rather than early-onset AD.

1.5.3 Implications for future research and clinical practice

1.5.3.1 Research examining memory

Research should firstly examine memory in the DS population. This review has shown that the changes in memory functioning in DS cannot be fully examined as there is little known about 'normal' memory functioning in this population. This research would also enable a more robust examination of what tests can assess memory and other types of cognitive functioning.

In order to fully understand and develop our knowledge base of memory functioning in DS it is essential to complete further research. This should focus on developing and adapting neuropsychological tests for use with people with DS. Additionally, substantial large scale research studies should be conducted to enable standardised data in which performance on memory assessments is stratified by age and intellectual abilities (i.e. IQ). In the general population, this information provides the most robust information about cognitive performance (see Salthouse, 2010). Only once there is a clearer understanding of memory functioning as people with DS age 'normally', will clinicians be able to differentiate between 'normal' and 'pathological' ageing.

1.5.3.2 Research assessing 'normal' ageing changes in DS

Due to the difficulties assessing for AD as outlined in the introduction, it is essential that the research examining 'normal' ageing is comprehensive and sufficiently thorough to assess for the possibility of AD in their participants so not to confound the 'normal' ageing literature.

Longitudinal designs are most suited to research into ageing and can offer stronger inferences from their results in terms of the rates of decline amongst individuals (Hofer & Sliwinski, 2001). Additionally, they can make stronger

assertions regarding the association between different variables than cross-sectional designs (Christensen, 2001). Larger samples are needed which should be monitored over a substantial period of time in order to observe any subtle changes. Multi-centre studies would be more beneficial as this would allow for larger groups of people with DS to be recruited as well as being able to explore the use of different types of neuropsychological tests. This research would help to identify methods for differentiating between 'normal' ageing and AD. This, in turn, would also help clinicians to detect AD in this population and allow the implementation of early interventions for specific cognitive impairments and AD.

Therefore, future research examining 'normal' ageing needs to incorporate and clearly report on the following:

At intake:

1. Exclude for AD by:
 - a. Using diagnostic guidelines used for the assessment of those suspected of developing AD. The working group recommends the use of ICD-10 (Aylward et al., 1997).
 - b. Including participants at approximately 30 years of age to reduce the risk of AD and to ensure a thorough and comprehensive baseline level of cognitive functioning and daily living abilities.

During the study:

2. A valid and reliable neuropsychological battery of tests should be used consistently.
3. Regular screening assessments for the onset of AD
 - a. Including direct and informant measures.
 - b. Multidisciplinary assessment of suspected AD.
 - c. Health checks to assess for conditions which may mimic AD symptomology.
 - d. Assessment of daily living skills, personality and mental health.
4. Assessment of different cognitive functions (including different types of memory abilities).

These criteria are essential in order to fully establish the trajectory of cognitive changes with 'normal' ageing in the DS population and to differentiate this from 'pathological' ageing.

1.5.5 Conclusions

The aim of this review was to increase our understanding of memory changes associated with 'normal' ageing in adults with DS. From the findings discussed, there is currently insufficient evidence to address this research question. The studies included in this review were confounded by significant methodological limitations and the inherent difficulties conducting research in this area has limited the data available for review.

This review has highlighted the difficulty of assessing memory functioning in the DS population. It is apparent that more knowledge is needed about people with DS and their cognitive abilities. Further concurrence is needed on the types of memory functioning that require assessment, which neuropsychological tests can be used and to determine what factors mediate and moderate memory functioning in people with DS. Only with increasing our understanding of the 'normal' memory functioning in people with DS, will we be able to identify and assess for pathological ageing in this at risk population.

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Chapter 2: Overview

The systematic review titled “Memory changes associated with ‘normal’ ageing in adults with Down syndrome: A systematic review” (Part I: Chapter 1) demonstrated that further research is needed to understand ‘normal’ ageing in adults with Down syndrome and intellectual disabilities. This is essential in order to understand how ‘normal’ ageing differs from ‘pathological’ ageing as this will aid dementia diagnosis. In order to detect changes in cognitive functioning, valid and standardised neuropsychological assessments are needed which are applicable for people with Down syndrome and intellectual disabilities. Therefore, the following empirical research project titled ‘Convergent validity of the Visual Association Test (VAT) in adults with intellectual disabilities’ was conducted with the aim of exploring this aspect of construct validity in a sample of adults with intellectual disabilities. This is followed by an extended report of the methodology (Chapter 4). Chapter 4 will be written in accordance with the journal article (i.e. Harvard style guidelines).

PART II

EMPIRICAL STUDY

CHAPTER 3: JOURNAL ARTICLE

Convergent validity of the Visual Association Test (VAT) in adults with intellectual disabilities

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*This article has been written in accordance with the Journal of Intellectual Disability
Research - author guidelines (Appendix 5)*

ABSTRACT: EMPIRICAL STUDY

Background: Neuropsychological tests of memory are believed to offer the greatest sensitivity at detecting people at risk of developing dementia. However, there is a paucity of validated, standardised and appropriate neuropsychological assessments of memory for adults with intellectual disabilities. This study examines the one aspect of construct validity (i.e. convergent validity) of an associative memory test (Visual Association Test; VAT) in adults with intellectual disabilities.

Methods: 40 participants (18-45 years) were recruited from Community Learning Disability Teams. Participants completed the VAT and subtests of the modified Cambridge Cognitive Examination (CAMCOG-DS). IQ was assessed using the Wechsler Adult Intelligence Scale, fourth edition (WAIS-IV). Correlational analysis of the test variables was carried out. Participants with a diagnosis of dementia were excluded from the study.

Results: All participants performed well on the VAT irrespective of age, gender or IQ. It was well received by participants. No significant correlations were found between the VAT and the subtests of the CAMCOG-DS or with the subtests of the WAIS-IV. Therefore, there was no evidence of convergent validity with these tests in this sample of participants.

Conclusions: While the VAT was found to be an easy and quick test to use with people with ID and all participants scored above 'floor' level, it was not found to have convergent validity with the CAMCOG-DS. Further research is needed to determine if the VAT represents a useful tool for assessment with this population.

Keywords: intellectual disabilities, memory, neuropsychological test, Visual Association Test, convergent validity.

Introduction

Alzheimer's disease (AD) is a progressive neurodegenerative disease which is the most common cause of dementia in the older adult population (Holtzman et al. 2011). AD is characterised by cognitive changes, in particular a deterioration in memory, as well as changes in the aptitude to perform everyday activities of daily life (Dickerson & Sperling 2008). A systematic review of the current evidence base for AD reported prevalence rates of 683,597 people suffering from AD in the UK with this being projected to increase by 38 per cent (940,110) by 2021 and by 154 per cent (1,735,087) by 2051 (Knapp & Prince 2007).

Dementia of the Alzheimer's kind is also the most common cause of dementia in people with intellectual disabilities (ID) (e.g. Strydom et al. 2007). People with ID have an increased risk of acquiring AD as they age, compared to the general population (British Psychological Society & Royal College of Psychiatrists 2009). People with Down syndrome (DS), in particular, have an increased risk of acquiring AD early in life (e.g. Tyrell et al. 2001) some 30-40 years earlier than the general adult population (e.g. Holland et al. 1998). With the rise in life expectancy, the incidence of AD is also predicted to increase in the future (Holland 2000). Therefore, AD will

place increasing demands on the NHS in the coming years, and research on early diagnosis has become a national priority (Department of Health 2009; Scottish Government 2010).

Early diagnosis of AD is vital if pharmacological therapies are to be effective. Evidence has demonstrated that in the general population cholinesterase inhibitors are most effective when given at the earliest point prior to significant neuronal damage occurring (see Birks 2006 for a review). However, other non-pharmacological treatment approaches may also be beneficial. In a recent Cochrane review, Cognitive Stimulation Therapy (CST) (a psycho-social group-based intervention) was shown to be effective in improving the cognition of people with mild-moderate dementia in the general population (Woods et al. 2012). Regardless of the treatment approach used, early diagnosis allows for effective care planning for individuals and their families (National Institute for Health and Clinical Excellence NICE 2006; Scottish Intercollegiate Guidelines Network SIGN 2006).

Neuropsychological assessment is increasingly being recognised as having a crucial role, especially in the early identification of cognitive decline associated with AD (NICE 2006; SIGN 2006). Neuropsychological tests may be the most sensitive tools for identifying those at risk of developing the

disease (Lezak et al. 2004). There are a wide range of tests available for use in the general population (see Lezak et al. 2004). However, there is a paucity of neuropsychological assessments which are validated, standardised and appropriate for application with people with ID (Masson et al. 2010).

One of the main obstacles for developing neuropsychological tools for the ID population is their pre-existing intellectual disabilities (Crayton et al. 1998). Neuropsychological assessments developed for use in the general population are often too complex and dependent on verbal abilities which can result in 'floor effects' when applied to this population (Crayton et al. 1998). That is, the majority of people with ID score in the extremely low range or at zero on tests. This results in difficulties differentiating changes in cognitive ability associated with the onset of AD from difficulties in cognitive ability due to the ID. In addition, co-morbid health conditions, such as depression, epilepsy, and hyperthyroidism, are common in people with ID and can mimic the presence of AD or confound the test results (e.g. Burt et al. 1992; Das et al. 1995a; Devenny et al. 1996; Hanney et al. 2009).

Accordingly, working groups have suggested that a standardised battery of tests should be employed longitudinally to assess dementia (Burt & Aylward 2000). In other words, persons with ID are assessed prior to the typical age

when they are vulnerable to AD and periodically reassessed to monitor for any decline in functioning. Accordingly, in recent years, there has been an increasing interest in the neuropsychological functioning of people with ID, exploring what tests can be used and whether the tests can identify changes in functioning over time (see Prasher 2009 for a review). Neuropsychological assessments used in the adult population have been modified for use with people with ID, for example, the Cambridge Cognitive Examination (CAMCOG-DS; Ball et al. 2006) and the Test for Severe Impairment (Albert & Cohen 1992). Measures used in the child population have also been modified and validated for use with people with DS (RBMT-C; see Wilson & Ivani-Chalian 1995). However, more research is needed on the adaptation of tests that have been shown to be sensitive to dementia in the general population.

In the general population, episodic memory has been found to deteriorate in the initial stages of AD (Hodges 2000). Deteriorations in episodic memory are allied with atrophy in the medial temporal lobes (e.g. Braak & Braak 1991; Ewers et al. 2011). Additionally, the earliest neuropathological indicators of AD are the presence of neurofibrillary tangles and amyloid plaques in these regions and the neighbouring hippocampus (e.g. Geula 1998; Visser et al. 2002).

Episodic memory is regarded as information which is received and stored about events and the relationships about these events (Tulving 1972). This type of memory is assessed by using recall and recognition tasks. For example, people are presented with visual or verbal information (e.g. objects or lists of words) asked to name them and then recall or recognise the information shown previously (Cabeza et al. 1997). In AD, both recall and recognition are affected over time (Hodges 2000). Free delayed recall is believed to be the measure which is sensitive to detecting the onset of AD (e.g. Thompson et al. 2011). However, poor performance on these tasks may be due to the difficulty placed on other cognitive functions or may be influenced by anxiety and depression (e.g. Kizilbash et al. 2002). People with specific conditions such as depression (e.g. Turner et al. 2012), Huntington's disease (e.g. Montoya et al. 2006) and Parkinson's disease (e.g. Elgh et al. 2009), demonstrate more difficulties with free recall tasks. Recall is also more influenced by normal ageing in the general population than recognition (e.g. Parker et al. 2004).

It is also imperative to assess recognition memory as deficits in this ability indicate that information has not been consolidated or stored properly, which is a hallmark of AD (Tierney 2001). Recognition tasks are not as demanding as recall tasks (Jarrold et al. 2007). Testing recognition can help to

differentiate between AD and other types of dementia (Graham et al. 2004). Furthermore, combining recall and recognition tasks can allow distinction between a retrieval or an encoding problem (Lezak 2004). Researchers argue that all memory tests should include a recognition trial to examine whether information has been encoded (Brown et al. 2010). This is especially important when free recall is impaired (Lezak 2004).

Cued recall is also believed to be a more specific marker for diagnosing AD (Buschke et al. 1997; Fuchs et al. 2012). Cued recall provides a cue at the time of encoding to aid retrieval of the target information (Lezak 2004). Furthermore, adding a cue at the time of encoding the target, raises recall to the level of recognition (Lindeboom et al. 2002).

The Visual Association Test (VAT) is a cued recall test that has been used in the general population (Lindeboom et al. 2002). It is a useful assessment for detecting early stage AD in the older adult population. It has also shown superiority and specificity over other tests of recognition (Fuchs et al. 2012). The VAT has also demonstrated the ability to discriminate AD from depressed and healthy individuals (Dierckx et al. 2007). Furthermore, studies have shown relationships with the VAT and hippocampal functioning (e.g. Henneman et al. 2009).

It has several attractive properties including that it is easy to administer, simple, quick to complete and 'it is not confounded by age, education or depression' (Lindeboom et al. 2002, pp. 132). It also does not rely heavily on language ability. Within the general population it has been shown to correlate with the Cambridge Cognitive Examination (CAMCOG) (Lindeboom et al. 2002) which is a neuropsychological test battery used in the general population that has been used to aid the assessment of dementia (e.g. Huppert et al. 1996). Specifically, the VAT corresponded with memory items (e.g. recognition) in the CAMCOG and thus, demonstrated convergent validity.

The advantages of the VAT indicate that it may be a suitable tool for assessing memory in people with ID. There is also the potential for the VAT to screen for dementia in this population. However, before its usefulness as a screening tool for dementia can be examined, it is important to explore how people with ID perform on the test. If it can be shown that they can perform on the test above the 'floor' level, it may prove to be a useful neuropsychological test of associative memory in the ID population.

There is limited research examining how people with ID perform on neuropsychological tests of memory. Of the evidence available, people with

mild ID have been shown to have more difficulty on tests of free recall than on tests of recognition (e.g. Martin et al. 2000; Van der Molen et al. 2010). For example, Martin et al.'s (2000) study of adults' (aged 19-58 years) performance on the Rivermead Behavioural Memory Test showed that people with mild ID (FSIQ 55-75) performed best on tasks of visual memory and that they found verbal recall the most difficult. Van der Molen et al. (2010) confirmed these findings in their sample of young adults (aged 13-17years) with mild ID (FSIQ 55-75). They found that verbal recall was poorer compared to matched controls and those with ID showed a strength in visual recognition.

A recent meta-analysis (Lifshitz et al. 2011) found that performance on recall and recognition tasks can be improved in people with ID by increasing the depth of processing (e.g. asking participants to name the object to be recalled as this improves semantic encoding) as well as using the visual modality rather than verbal modality. Therefore, the VAT may be a useful tool given that it incorporates these features. It is also a cued recall test, which should be an area of strength for people with ID due to their performance on recognition tests and their difficulties with recall tasks.

The aim of the present exploratory study was to conduct a preliminary examination of the psychometric properties of the VAT to help determine if it was a suitable measure of memory in adults with ID. It was hypothesised that participants in this current study would score between four and six on the VAT as this is consistent with performance in the general population, whereby those without any impairment generally perform near or at the ceiling of the test (Lindeboom & Schmand 2008). This includes an examination of one aspect of construct validity, namely convergent validity, of the VAT with the adapted CAMCOG-DS (Ball et al. 2006). This is following research which has examined the relationship between the VAT and CAMCOG in the general adult population (Lindeboom et al. 2002).

The current study had additional aims including examining the relationship between the VAT and all subtests of the WAIS-IV in order to investigate the psychometric properties of the VAT further. There was insufficient information to make an *a priori* hypothesis. Additionally, the effect of IQ, age and gender on VAT performance will be examined given the exploratory nature of this study. Furthermore, the reliability of the VAT will be examined within the current sample.

The following hypotheses were explored:

Hypothesis 1: Participants will score between four and six on the VAT (Trial 1).

Hypothesis 2: There will be a significant positive correlation between performance on the VAT and the picture recall and picture recognition subtests of the CAMCOG-DS (Ball et al. 2006).

Method

Design

A cross-sectional, correlational design was adopted to examine the performance of a sample of participants with mild-moderate intellectual disabilities on the Visual Association Test (Lindeboom & Schmand 2008). The study was granted approval from the South East of Scotland Research Ethics Committee.

Participants

Of the potential participants that the researcher met: four could not provide informed consent; two participants did not meet the inclusion criteria; seven participants decided not to take part; and one participant asked to stop after the first trial of the VAT. The final sample consisted of 40 adults (21 males and 19 females) aged between 18 to 44 years (mean age 31.08 years; SD 8.075) with mild-moderate ID (mean FSIQ 59.10, SD 7.57; range 46-73). All participants were of mixed aetiology including: Down syndrome; Prader-Willi syndrome; Fragile X syndrome; Velocardiofacial syndrome; and ID (not otherwise specified).

Recruitment

In order to be eligible for inclusion, all potential participants had to be between 18 and 45 years of age; fluent in English; and able to provide consent. Potential participants were excluded if they had: significant visual or hearing impairments; a diagnosis of dementia; significant personality and behavioural problems or a severe ID.

Participants were recruited via health professionals from Community Learning Disability Teams based in the North of Scotland. Those who were interested in participating were subsequently contacted by the researcher, who provided further details about the study.

Information was provided in an accessible format and this was reviewed at a focus group for people with ID prior to commencement of the study. Accessible information was provided to enable potential participants to make informed decision regarding participation in the study. BPS guidelines and other relevant guidelines of assessing for consent were adhered to (BPS 2010; Dobson 2008). Consent was gathered by means of a written consent form which was witnessed by their clinician or relative to ensure consent was acquired appropriately. However, consent was viewed as an ongoing process throughout the study.

Measures

Visual Association Test

The Visual Association Test (VAT; Lindeboom et al. 2002) consists of six cards depicting line drawings of interacting objects (e.g. an ape holding an umbrella) and six cards depicting only one of the objects as a cue. The VAT is valid and reliable with an internal consistency of 0.84 on the first trial and 0.86 for those who completed two trials on Form A (Lindeboom and Schmand 2008). Its validity has been replicated by others (e.g. Diercks et al. 2007; Henneman et al. 2009; Kulansky et al. 2002). In the current study, Cronbach's alpha was 0.41 for the first trial and 0.66 for the two trials. An acceptable value of alpha is above .7 (see Pallant 2010).

Intellectual Functioning

The Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV; Wechsler 2008) was used to assess intellectual functioning. It includes a broad battery of subtests and has excellent psychometric properties. The WAIS-IV was normed on a large sample of individuals ($n = 2200$) of adults between the age of 16-90 years. The WAIS-IV is both reliable and valid with an internal consistency of 0.98 for the Full Scale IQ. It has been shown to be a strong measure of intelligence (e.g. Canivez & Watkins 2010).

Cambridge Cognitive Examination adapted for people with Down Syndrome and Intellectual Disabilities

Visual incidental learning was also measured using the picture recall and picture recognition subtests of the modified Cambridge Cognitive Examination, CAMCOG-DS. These subtests on the CAMCOG have been shown to correlate with the VAT in the general population (Lindeboom et al. 2002). The CAMCOG-DS is the neuropsychological section of the CAMDEX-DS (Ball et al. 2006) which was adapted for use with people with DS and ID. Although validity for the CAMCOG-DS has not yet been established, the CAMCOG has been shown to be reliable and has excellent internal reliability. Cronbach's alpha was 0.82 and 0.89 in different samples (Holland and Ball 2009).

Procedure

All participants were administered the neuropsychological tests in the same order: (1) VAT; (2) WAIS-IV (if applicable) and (3) Sub-tests from CAMCOG-DS. If the WAIS-IV assessment had been previously completed, this was not repeated. A break of 20 minutes between the administration of the VAT and the CAMCOG-DS was provided to reduce the likelihood of participants confusing the test items.

The standardised protocols were followed for administration of the WAIS-IV and CAMCOG. Adaptations were made to the administration of the VAT; Form A was used, which involved two trials which are suitable for 'younger but poorly testable patients' (Lindeboom & Schmand 2008, pp. 27) in conjunction with the instructions from form B as these were deemed to be easier for those with ID to understand. Testing lasted between thirty minutes and two hours and breaks were also provided. A second appointment was provided for individuals completing the WAIS-IV.

VAT Administration

In the first trial, the six cards of interacting objects were presented. The participants are asked to name the associated objects to maintain attention (i.e. frying pan and dice). The cue cards (showing only one of the objects) were then presented without delay. Participants were asked, 'what object is missing?' For example, 'what was in the frying pan?'. Responses were accepted and awarded one point if they were clear in differentiating between the target object (e.g. dice) with the other objects presented in the test. Acceptable responses were allowed to be spoken, written, illustrated or imitated. The points from the two trials were then totalled awarding a maximum score of 12 points for the test. The second trial is only commenced

if participants score less than the maximum score of six on the first trial, otherwise, full points are awarded for the second trial.

CAMCOG Subtests Administration

Initially, participants were asked to name the pictures of everyday objects (e.g. shoe, computer and scales). Participants were asked to recall the names of the objects following a delay. There was then followed by a recognition trial whereby participants were presented with the pictures of the objects they had seen and other similar objects (e.g. three shoes). They were then asked to identify which object they had seen before. Each subtest awards six points.

Rationale for Data Utilised in the Current Study

The aim of this study is to examine the properties of the VAT in a sample of participants without dementia. In order to examine this, the data from VAT Trial 1 will be used as it examines whether items have been associated or not in memory. That is, to see if the target and the cue are perceived as one object and with a cue provided whether the target is accurately recalled. It is believed that Trial 2 examines whether participants can learn after a repeated trial and thus demonstrate an incidental learning effect. Thus, it is expected by the authors of the VAT that performance will improve on Trial 2 (if this is

administered). Given that the purpose of the paper is to determine whether the VAT has convergent validity with other similar tests, Trial 1 will be used as the picture recall subtest (CAMCOG-DS) only involves one learning trial. Using the Trial 2 data could potentially confound the results due to the expected learning effect.

Results

Data Analysis

Data were screened to assess for normality, homogeneity of variance, skew and kurtosis to ensure agreement with statistical assumptions. Violations of normality were found for the VAT, CAMCOG-DS and WAIS-IV following visual inspections of the histograms and Q-Q plots. This was confirmed by Shapiro-Wilk's test. This test was used as it is more accurate than its counterpart, Kolmogorov-Smirnov, when samples are smaller (Field 2009). Although recommended, the distributions were not transformed in order to use parametric analysis (see Tabachnick & Fidell 2001). Instead, non-parametric analysis was used as the intention was to simplify the interpretation of the findings. Furthermore, given that the VAT scores are categorised on an ordinal scale, using non-parametric tests was more appropriate (Field 2009). The raw scores of tests were used rather than transforming scores into a common metric such as t scores (Crawford 2004). As multiple correlations are being carried out, a Bonferroni calculation was considered in order to reduce the likelihood of a type one error, however, this was deemed to be too conservative and would increase the likelihood of a type two error. Instead, a conservative p-value of .01 was applied (Field, 2009).

Descriptive Data

Table 1 presents the participants' scores on all the neuropsychological tests and the mean and median score and standard deviation.

Table 1. Means and Standard Deviations of Test Scores (n=40).

Test		<i>Mean</i>	<i>SD</i>	<i>Range</i>	<i>Median</i>	<i>Max Score</i>
VAT	Trial 1	5.7	0.61	(4-6)	6	6
	Total 2 trials	11.6	0.90	(8-12)	12	12
CAMCOG-DS	Picture recall	1.95	1.84	(0-6)	1	6
	Picture recognition	5.65	0.74	(4-6)	6	6
WAIS-IV	FSIQ	59.10	7.57	(46-73)	59	160
Subtests	Arithmetic	3.55	1.50	(1-8)	4	19
	Block Design	3.93	2.30	(1-10)	4	19
	Coding	3.20	2.02	(1-9)	3	19
	Digit Span	3.68	2.33	(1-10)	4	19
	Information	4.83	1.90	(3-11)	4	19
	Matrix Reasoning	3.75	1.53	(1-7)	3	19
	Similarities	4.00	1.63	(1-7)	4	19
	Symbol Search	3.35	2.12	(1-9)	3	19
	Visual Puzzles	4.55	1.20	(2-7)	5	19
	Vocabulary	3.98	1.25	(2-8)	4	19

Hypothesis 1: Participants will score between four and six on the VAT (Trial 1).

Table 2. Distribution (in %) in Memory Test scores (n=40)

Test score	0	1	2	3	4	5	6
CAMCOG-DS picture recall	55.0	22.5	10.0	12.5	10.0	15.0	0.0
CAMCOG-DS picture recognition	0.0	0.0	0.0	5.0	0.0	20.0	75.0
VAT (1 trial)	0.0	0.0	0.0	0.0	7.5	15.0	77.5

As can be seen from the descriptive data shown in Table 2 participants' scores ranged from four to six. This supports the prediction made.

Hypothesis 2: There will be a significant positive correlation between performance on the VAT and picture recall and picture recognition subtests of the Cambridge Cognitive Examination for people with DS and ID (CAMCOG-DS; Ball et al. 2006).

As can be seen from the descriptive data in Table 1, 55 per cent of participants scored at the 'floor' of the recall subtest of the CAMCOG-DS. No significant relationship was found between performance on the VAT Trial 1 and picture recall ($T=0.005$, $p=.974$). However, the majority of participants (75%) obtained full marks for the picture recognition trial. Nevertheless, no

significant relationship was found between performance on the VAT Trial 1 and picture recognition ($T=0.82$, $p=.595$).

Relationship between VAT, IQ, age and gender

In order to determine if performance on the VAT was affected by the degree of intellectual disability (IQ), age or gender, a series of analyses were conducted to examine this.

Kendall's Tau (non-parametric) test was used to correlate VAT scores with IQ and age. Field (2009) argued that this test should be employed with small samples where there are scores with comparable ranks. Furthermore, it is a more accurate representation of correlations in the population which should lead to better generalisations to the real world (e.g. Clark-Carter 2010; Field 2009). No significant correlations were found between the VAT (Trial 1) and IQ ($T=0.84$, $p=.520$); nor between the VAT (Trial 1) and age ($T= -0.35$, $p=.784$) as tested by Kendall's Tau. Furthermore, the Mann-Whitney U test revealed no significant differences between males and females on the VAT (Trial 1) ($U=183.5$, $z= -0.595$, $p=.522$).

Relationship between VAT and WAIS-IV subtests

The relationship between the VAT and WAIS-IV subtests were conducted to examine the psychometric properties of the VAT further. No correlations were found between the VAT (Trial 1) and any of the WAIS-IV subtests at $p < 0.01$ (Arithmetic $t = .302$; Block design $t = .142$; Coding $t = .085$; Digit span $t = -.700$; Information $t = .107$; Matrix reasoning $t = .059$; Similarities $t = .265$; Symbol search $t = .107$; Visual puzzles $t = -.115$; Vocabulary $t = .194$)

Discussion

Main Findings

This research study examined the convergent validity of the Visual Association Test (VAT) in 40 adults with mild-moderate intellectual disabilities (ID). Firstly, as was predicted, the participants scored between four and six on the VAT. No participants scoring at the 'floor' level and 77.5 per cent obtaining the maximum score. This is consistent with the general population, whereby those without any impairment generally perform at or near the ceiling of the test (Lindeboom & Schmand 2008). The present study also found that performance on the VAT was not affected by age, IQ or gender. These findings are also consistent with the literature examining performance on the VAT in the general adult population (Lindeboom et al. 2008). These findings highlight that the VAT could be a potentially useful neuropsychological tool for people with ID. Furthermore, the VAT may prove to be useful in the assessment of dementia given that participants scored highly on the test, indicating scope for demonstrating change on the test. Neuropsychological tests that have been used in the general adult population when applied with people with ID often result in 'floor' effects (Crayton et al. 1998), hence, the VAT has promise in its application in the ID population.

The VAT has been found to correlate with the memory items of the CAMCOG in the general population (Lindeboom et al. 2002), however the present study found no significant relationship between the VAT and picture recall and recognition subtests of the CAMCOG-DS. The former result may be because people with ID have difficulties with tasks of free recall (e.g. Martin et al. 2000; Van der Molen et al. 2010). Additionally, the validity of the CAMCOG-DS is yet to be established and this may be another reason for not finding a relationship. With regard to the picture recognition subtest, descriptively participants performed similarly on this and the VAT, with 75 per cent of participants obtaining a score of six on recognition and 77.5 per cent of participants obtaining a score of six on the VAT. This suggests that the VAT may show convergent validity in this population, however, a statistically significant correlation was not found. One of the reasons for this may be because there was a limited range of scores on all of the tests in this study, with most participants performing at the ceiling of the test, scoring between four and six (total score 0-6). Nevertheless, the findings have demonstrated that participants with ID performed better on tasks of recognition and cued recall than on tasks of free recall which is supported by the literature (e.g. Martin et al. 2000; Van der Molen et al. 2010). This suggests that these types of tests may be more applicable for this population.

Further analysis of the data with regards to the psychometric properties of the VAT showed that there were no correlations between the VAT and subtests of the WAIS-IV. This provides some support for the VAT being conceptually different than the requirements of the subtests of the WAIS-IV. This highlights that the VAT is primarily assessing memory rather than another cognitive function (i.e. processing speed). It also lends support for the VAT tapping into different regions of the brain than the WAIS-IV subtests. Unlike the VAT, none of the WAIS-IV subtests have been allied with the medial temporal lobes. For example, the digit span subtest of the WAIS has been related to the prefrontal cortex region (Kanecho et al., 2011). However, the VAT has been shown to have a relationship with atrophy in the medial temporal lobes (Lindeboom & Schmand, 2008). Further research is needed to substantiate this using functional MRI within the ID population.

The reliability of the VAT was examined, however, the value of alpha was poor. There are several potential reasons for this finding. Firstly, it may be due to the small sample size in this study. Secondly, Cronbach's alpha can also be sensitive to the number of items in the scale (Pallant 2010). Lastly, the test may not be reliable for this particular ID sample. This requires further research.

Strengths & Limitations of Study

One of the strengths of this study was that it included participants with a variety of genetic conditions (e.g. Down syndrome, Fragile X, Prader Willi syndrome) all of whom obtained high marks on the VAT. It is of note that the two adults with DS included in the study obtained full marks on the VAT. People with DS have an increased risk of developing AD than the general population (e.g. Tyrell et al. 2001), therefore, finding tests that are sensitive to changes in memory, particularly paired associates tasks, is of extreme importance, as it is argued that they are more sensitive to changes in the hippocampus (e.g. Henneman et al. 2009). This exploratory study suggests that the VAT is one such test that could have potential in this area, as well as being applicable to a range of adults with ID. However, further research is needed to corroborate these findings with larger samples.

A limitation of the study is that the variety of genetic conditions in the participant sample means that the group was not homogenous and thus, the study does not provide norms for a specific group. It is therefore, not clear what factors may have moderated or mediated performance on the VAT. While the study found no relationship between performance on the VAT and age, gender and level of ID, the study did not control for other factors that have been found to confound test results, such as health conditions (e.g. Burt

et al. 1992; Das et al. 1995; Devenny et al. 1996; Hanney et al. 2009). Further research with larger sample sizes is needed to explore these potential relationships further.

The present study provided a useful examination of the VAT with people with ID, however it is limited in that it has only focused on convergent validity and reliability when examining the psychometric properties of the VAT. Future studies which explore additional forms of validity and reliability of the VAT with this population are needed.

Another limitation of the study is the relatively small number of participants. This is likely to have impacted on the statistical power of the study. For example, research has found that other neuropsychological tests are influenced by IQ, such as the California Verbal Memory Test (CVLT; Rapport et al. 1997), whereas the present study found no relationship between IQ and performance on the VAT. It is unclear, whether this result is an artefact of the relatively small sample size.

Future Research & Clinical Implications

It is premature to suggest that the VAT can be used as a test of associative memory in people with mild-moderate ID as the psychometric properties of

the VAT requires further examination. Future research could examine the psychometric properties of the VAT in larger homogenous samples, specifically with adults with DS, given their increased risk of developing AD. This would be beneficial as a multi-site research project and it would increase the generalisability of the findings. Future research could then examine the application of the VAT in the assessment of AD in the DS and ID population.

In addition to the psychometric properties examined, there are practical and clinical advantages of using the VAT in this population as it is simple, quick to complete and it was well received by all of the participants. Furthermore, given the lack of available memory tests for the ID population (Masson et al. 2010), the VAT has potential to be a welcome addition to the tests available.

Conclusion

This research study has shown that the majority of participants with ID scored highly on the VAT. Additionally, their performance was not affected by IQ, age or gender. However, the aim of this study was to examine the convergent validity of the VAT with the CAMCOG-DS but this was not demonstrated. Further research is therefore needed to determine if the VAT represents a useful assessment tool with this population by investigating its

validity in a larger sample. Following this, the ability of the VAT to screen for dementia in the ID population could be examined.

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CHAPTER 4: EXTENDED METHODOLOGY

4.1. Design

A cross-sectional, correlational design was adopted to examine a sample of participants with mild-moderate intellectual disabilities (ID) performance on the Visual Association Test (VAT). Correlational analysis was employed to compare the VAT with two subtests of the modified Cambridge Cognitive Examination (CAMCOG-DS; Ball et al. 2006). The relationship between Full Scale IQ scores (as measured by the Wechsler Adult Intelligence Scale, fourth edition, WAIS-IV; Wechsler 2008) age, gender, and the VAT, were also correlated. The independent variable was the presence of ID and the dependent variables were objective measures of memory.

4.1.1 Ethical approval

The study was appraised by the University of Edinburgh's academic staff. Ethical approval was permitted by NHS Lothian Research Ethics Committee (Appendix 6). Management approval was granted from NHS Highland and NHS Grampian to commence the research (Appendix 7).

4.1.2 Ethical considerations: Method of recruitment

Given that this study involved vulnerable adults, the recruitment of participants was accessed through clinicians already involved in their care. Staff were provided with an information sheet about the study (Appendix 10). All participants were aged between 18 and 45 years. Potential participants were provided with participant information booklets (Appendix 9 and Appendix 10) by clinicians already involved in their care and if willing to participate either contacted the researcher directly or asked their clinician or carer to do this. When they met with the researcher, potential participants were able to ask questions about the research prior to deciding whether to take part. An independent contact was available for people to contact as well. It was made clear that participation in the study was voluntary and that they could withdraw at anytime without having to give a reason. It was also emphasised that declining to participate at any point would have not affect their current care or future treatment. All participants were offered an option of receiving written feedback regarding their results after completion of the tests.

4.1.2.1 Ethical considerations: Development of participant information

As this study involved people with ID, time was taken to develop participant information in accessible formats. Two information sheets were developed:

one provided more detailed written information and the second was presented in a booklet form which contained both pictures and words (Appendix 9 and 10). The sheets were developed to provide the information in an accessible, easy to read format in line with standards (e.g. Inclusion Europe (n.d.); Scottish Accessible Information Forum 2001). An Accessible Information Officer in the Learning Disabilities Service reviewed this information at a focus group for people with ID prior to the study's commencement. The information was developed to provide accessible information in different formats to enable potential participants to make informed decisions regarding participation in the current study.

4.1.2.2 Ethical considerations: Consent to research

This study only included people who could provide informed consent. Nevertheless, the researcher was aware that there can be difficulties ensuring that people with ID can fully consent to participating in research (Cameron & Murphy 2006). For that reason, the British Psychology Society guidelines of conduct were adhered to (BPS 2010) and other guidance documents were considered (see Dobson 2008). In addition, the researcher discussed ways of communicating information with the Speech and Language Therapist in the Learning Disabilities Service prior to commencement of the study. This was

done in order to ensure that potential participants could understand the research and its consequences fully.

A witness, either a relative or clinician involved in the person's care was also present to ensure that consent was assessed appropriately. Potential participants were deemed to be able to consent if they could: understand the research study; the pros and cons of participating; communicate their decision; knew their participation was voluntary and that they could discontinue at any point. The researcher was aware that people might agree to participate without fully comprehending the implications (Arscott et al. 1998). In addition, the researcher paid attention to non-verbal cues as indicators of giving consent, such as eye-contact and body-language in addition to verbal responses (Cameron & Murphy 2006). Consent was gathered by means of a written consent form (Appendix 12). However, the researcher perceived consent as an ongoing process and therefore reminded participants prior, during and after testing that they could discontinue at any point without having to give a reason.

4.1.2.3 Ethical considerations: Psychological distress

It was recognised that the research process may uncover a clinical problem which had not been diagnosed. Therefore, consent was sought prior to

participation in the study for the researcher to contact the participants' General Practitioners if required.

4.1.2.4 Ethical Considerations: Fatigue

Participation in the study involved completing neuropsychological assessments for a period of thirty minutes to a maximum of two hours. All participants were therefore offered breaks during testing and further appointments were arranged if participants became fatigued.

4.2 Participants

All potential participants were: able to provide consent, aged between 18 and 45 years of age, and fluent in English. Potential participants were excluded if they had: a diagnosis of dementia; a severe ID; significant personality and behavioural problems; significant visual or hearing impairments. Participants were not excluded on the basis of general medical conditions such as diabetes, epilepsy, and high blood pressure. Instead, these were noted from participants' medical files with their consent.

Participants were recruited through contacting health professionals from Community Learning Disability Teams. The researcher met the teams and asked them to recommend people eligible to participate. Clinicians were

provided with further information about the study (Appendix 11). The clinician involved with the potential participant contacted them in the first instance and provided them with an information booklet (Appendix 9 and Appendix 10). Clinicians contacted the researcher with the details of those who agreed to find out more about the study. The researcher contacted potential participants and arranged an appointment. Information was provided about the study and an opportunity was given to ask questions about the study and discuss any concerns. A minimum of 24 hours was given to allow participants to consider whether to participate. A further appointment was offered at a location of their choice, either at their home or at a clinic. Those who agreed to participate and who were able to provide informed consent were provided with a written consent form (Appendix 12). Each item on the form was discussed by the researcher. For the majority of participants a clinician, family member or support worker was available to witness that consent had been gathered appropriately. However, the researcher put emphasis on the fact that participants could withdraw their consent at any time without having to give an explanation. Demographic information, specifically age, was collected.

4.2.1 Participant sample

There were a number of participants approached by clinicians who decided not to meet the researcher to hear more about the study. Unfortunately, clinicians did not provide exact numbers on how many people declined. Therefore, the exact response rate could not be calculated. Of the information that was available, 18 people who were approached did not wish to meet the researcher. Of the potential participants that the researcher met: four could not provide informed consent; seven decided not to take part; two did not meet the inclusion criteria; and one participant asked to stop after the first trial of the VAT. The final sample consisted of 40 adults (21 males and 19 females) aged between 18 to 44 years (mean age 31.08 years; standard deviation, SD, 8.075) with mild-moderate intellectual disabilities (mean FSIQ 58.80; SD 7.930 range 46-73).

Consent was gathered to obtain participants' medical files. Of the 40 participants, 12 had specific conditions including: Cerebral Palsy (n=3); Down syndrome (n=2); Foetal alcohol syndrome (n=1); Fragile X syndrome (n=1); Prader-Willi syndrome (n=2); Rubenstein Taybi syndrome (n=2); Turner syndrome (n=1). The other 28 participants had no specific diagnoses.

Participants had a range of medical and health diagnoses including: adhd; anxiety; autism; diabetes; epilepsy; fallot tetralogy; heart problems; myotonic dystrophy; scoliosis; and velocariofacial syndrome. The variety of conditions and related health diagnoses indicates that this is a clinical sample.

4.2.2 Sample size

Most studies have completed population studies and have not reported effect sizes or power calculations. The closest study which provides a rationale for the current proposed study was by Masson et al. (2010). They studied the correlations between the Tower of London test which measures executive functioning, with measures such as Wechsler Abbreviated Scale of Intelligence (WASI; Wechsler 1999), the Dysexecutive Questionnaire – Independent Rater (Burgess et al. 1996) and the Adaptive Behaviour Scale – Residential and Community: Second Edition (ABSRC:2; Nihira et al. 1993). They used a medium to large effect size of .40, set the alpha at .05 and aimed to recruit a sample size of 50, to provide power of .821. The study included 43 individuals with intellectual disability. It was calculated that Masson et al. (2010) had a large effect size in their study.

This study was used to determine the sample size for the current study. A power analysis program called G*Power3 (Faul et al. 2009) was used to

calculate the minimum number of participants necessary to detect a large effect size using correlations. A significance level of .05, at a power of .80 and with a large effect size .50, would require a minimum sample of 26 people to be included in the current study. However, given that the current study is examining memory, this empirical study applied a medium-large effect size which would require a minimum sample of 44 people.

Given that this study is exploratory and is examining the utility of a neuropsychological test in this population, the sample size is more than adequate for this purpose. Many research studies examining the utility of neuropsychological tests have not calculated effect sizes as they have examined performance on the measure prior to a larger research study being completed (e.g. Rivermead Behavioural Memory Test, Children's Version, RBMT-C; Hon et al. 1998). In this study, there were a total of 40 participants in the sample which meets the requirements of this exploration study.

4.3 Measures

4.3.1 Demographic characteristics

Basic information including age and gender were collected from the participants. Consent was acquired from participants to access their medical

records about any pre-existing medical conditions that may have impacted on their cognitive ability and neuropsychological testing. For example, depression and hyperthyroidism (Burt et al. 1992; Das et al. 1995; Devenny et al. 1996) and visual or hearing impairments (e.g. Hanney et al. 2009). Consent was also obtained to access the participants' psychology files for recent intellectual functioning assessment reports, specifically the Wechsler Adult Intelligence Scale, 4th Edition (WAIS-IV; Wechsler 2008).

4.3.2 Neuropsychological tests

The main aim of the research study was to examine the utility of the Visual Association Test (VAT) with adults with ID and to determine whether it is a suitable measure for adults with ID. In addition to this other tests were employed: WAIS-IV (Wechsler 2008) and two subtests of the Cambridge Cognitive Examination adapted for people with Down syndrome and intellectual disabilities (CAMCOG-DS; Ball et al. 2006). These were employed to assess intellectual functioning and visual incidental learning respectively. These neuropsychological tests will be examined and discussed in detail.

4.3.2.1 Visual Association Test (VAT; Lindeboom et al. 2002, 2008)

The VAT is a brief test of visual paired-associates learning based on imagery mnemonics. The VAT is a measure of episodic memory and is a visuo-spatial

cued recall task. It consists of six pairs of interacting objects presented as line drawings. The participant is asked to name the interacting objects then one of the objects is presented as a cue and the participant is asked to name the missing object. One point is awarded for each correct response. A maximum of six points are awarded. This procedure is then repeated for a second trial and a total of 12 points are awarded overall. The test predicts that the visual associated objects will be learned effortlessly and failure to do so is a result of problems with the encoding of new information. Thus the test was intended to detect anterograde amnesia and related disorders.

4.3.2.1.1 VAT: Reliability

The reliability of the VAT has been examined in terms of internal consistency, test-retest and parallel test reliability (see Lindeboom & Schmand 2008). The VAT has demonstrated good internal consistency. Form A, Cronbach's Alpha was 0.84 on the first trial and 0.86 for those who completed two trials. Test-retest reliability has been demonstrated for Form A. Parallel test reliability was examined by correlating Form A and B with 177 patients from Vrije University and demonstrated 0.74 and 0.84 for Trial 1 and Trials 2 correspondingly.

4.3.2.1.2 VAT: *Validity*

Validity was studied by the authors, Lindeboom and Schmand (2008), namely construct, discriminative, criterion and concurrent validity. Confounding influences were also examined. The VAT demonstrated good construct validity and correlates highly with the Cambridge Cognitive Examination (CAMCOG; Huppert et al. 1995; Roth et al. 1986). The VAT has high discriminative validity and can distinguish between people with Alzheimer's disease (AD) and healthy older people (Kulansky et al. 2002). This has been replicated by Dierckx et al. (2007) whereby the VAT classified those with AD, depression and healthy people correctly. Criterion validity was established by Lindeboom and Schmand (2008) who found a significant association with atrophy of the medial temporal lobes and low VAT-scores ($p=.007$). This has been replicated by other researchers (Henneman et al. 2009). The relationship between informal judgement of a subject's memory and VAT scores were also examined by the authors. They found a significant correlation ($p<.001$) between severe memory problems and low VAT scores. Concurrent validity was established by correlating the VAT Form A and CAMCOG sections on memory. The sum of memory and orientation subscales reached the highest correlations (i.e. .64, $p<.00001$) with the VAT. Confounding influences were examined and demonstrated that the VAT is not significantly associated with age, sex, educational achievement or

depression. Overall, the VAT is a highly reliable and valid test. Its high specificity in distinguishing AD has been demonstrated elsewhere (e.g. Dierckx et al. 2007; 2009; Fuchs & Pentxek 2011).

4.3.2.2. Wechsler Adult Intelligence Scale, Fourth Edition (WAIS-IV; Wechsler 2008)

The WAIS-IV was used as an assessment of cognitive ability. It includes a broad battery of subtests and has excellent psychometric properties. The WAIS-IV was normed on a large sample of individuals (n=2200) of adults between the age of 16-90 years. The WAIS-IV is both reliable and valid with an internal consistency 0.98 for the Full Scale IQ. It has been shown to be a strong measure of intelligence (e.g. Canivez & Watkins 2010).

4.3.2.3 Picture Recall and Picture Recognition: Cambridge Cognitive Examination, CAMCOG-DS (In Cambridge Examination for Mental Disorders of Older People with Down's Syndrome and Others with Intellectual Disabilities, CAMDEX-DS; Ball et al. 2006)

Originally, the CAMDEX was developed as a standardised assessment tool for use in the general elderly population for diagnosis of mental disorders, and more specifically for the detection of dementia (Huppert et al. 1995; Roth et al. 1986). The CAMDEX was modified for use with people with Down

syndrome and intellectual disabilities (Ball et al. 2004) in response to the need for suitable and valid measures of dementia in this population (Holland & Ball 2009).

The schedule consists of a number of useful assessment tools including a neuropsychological test battery, the Cambridge Cognitive Examination (CAMCOG). The CAMCOG measures the cognitive functions known to deteriorate in dementia. The structure of the CAMCOG-DS is the same as the CAMCOG with some modifications to make the tests suitable for people with intellectual disabilities. Hon et al. (1999) demonstrated that the CAMCOG could be used with people with Down syndrome and intellectual disabilities with some modifications (i.e. CAMCOG-DS). It correlates well with Mini Mental State Examination (MMSE; Folstein et al. 1975) and only a small percentage of their participants scored at the floor of the test (11%). Although validity for the CAMCOG-DS has not yet been established, the CAMCOG has been shown to be reliable and has excellent internal reliability. Cronbach's alpha was 0.82 and 0.89 in different samples. The test-retest reliability is excellent with a Pearson's correlation of 0.86 (Huppert et al. 1996; Holland & Ball 2009). The findings have been replicated by other studies, and demonstrate that the CAMCOG has high sensitivity and specificity for the diagnosis of dementia (e.g. Lindeboom et al. 1993).

The picture recall and picture recognition subtests of the CAMCOG-DS were administered as another test of visual incidental learning similar to the VAT. These subtests on the CAMCOG have been shown to correlate with the VAT in the general population (Lindeboom et al. 2002).

Recall and recognition are two main retrieval processes which allow clinicians to test how information has been stored (Baddeley 2004). Picture recall asks participants to recollect what pictures they have seen previously following a delay. One point is awarded for each correctly recalled item. A maximum of six points can be achieved. Picture recognition asks participants to point to the picture they saw previously from three pictures, only one of which the participant saw previously. Similarly, one point is awarded for each correctly identified picture. A maximum of six points can be achieved.

Efforts were made to collect information on the performance of people with DS and ID on the CAMCOG-DS from the authors of the epidemiological study (Hon et al. 1999). However, this information was not received prior to completion of this study.

4.4 Procedure

4.4.1 Administration

All participants were administered the neuropsychological tests in the same order: (1) VAT; (2) WAIS-IV (if applicable) and (3) Sub-tests from CAMCOG-DS. If the WAIS-IV assessment had been previously completed, this was not repeated. A break of 20 minutes between the administration of the VAT and the CAMCOG-DS was provided to reduce the likelihood of participants confusing the test items from each test.

The standardised protocols were followed for administration of the WAIS-IV and CAMCOG-DS. Adaptations were made to the administration of the VAT; Form A was used, which involved two trials which are suitable for 'younger but poorly testable patients' in conjunction with the instructions from Form B as these were deemed to be easier for those with an intellectual disability to understand (Lindeboom & Schmand 2008, pp 27). Testing lasted between thirty minutes and two hours and breaks were also provided. A second appointment was provided for individuals completing the WAIS-IV. Participants were given the option of requesting written comments on their performance.

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APPENDICES

Systematic Review

1. Research in Developmental Disabilities (RIDD) author guidelines
2. Search strategy
3. Quality criteria adapted from Scottish Intercollegiate Guidelines Network (SIGN)
4. Summary of quality ratings of included papers

Empirical Study

5. Journal of Intellectual Disability Research (JIDR) author guidelines
6. Ethical approval: Scotland A Research Ethics Committee
7. Research & development approval: NHS Highland
8. Participant (easy-read) booklet
9. Participant information sheet
10. Staff information sheet
11. Participant consent form

Appendix 1: Author Guidelines, Research in Developmental Disabilities (RIDD)



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Appendix 2: Search strategy

Table 1. Search strategy

<i>Source</i>	<i>Search Strategy</i>	<i>Results</i>	<i>Hits</i>
NICE / SIGN Guidelines	Down Syndrome, Aging, Memory	NICE = 7 SIGN = 0	NICE = 0 SIGN = 0
Cochrane Central Register Control Trials / Cochrane Systematic Review	Down* Syndrome, Ag*ing, Memory	7296	0
OVID Databases: Medline (1946 to July 02)	<ol style="list-style-type: none"> 1. (Cognit* or Memory).mp 2. exp Neuropsychological Tests/ 3. 1 or 2 4. exp Down Syndrome/ 5. 3 and 4 6. exp Aging/ 7. 5 and 6 8. limit 7 to ("young adult and adult (19-24 and 19-44)" or "middle age (45 to 64 years)" or "middle aged (45 plus years)" or "all aged (65 and over)" or "aged (80 and over)") 	53	1
OVID Databases: Embase (1974 to 2012 July 02)	<ol style="list-style-type: none"> 1. (Cognit* or Memory).mp 2. exp Neuropsychological Tests/ 3. 1 or 2 4. exp Down Syndrome/ 5. 3 and 4 6. exp Aging/ 7. 5 and 6 8. limit 7 to (adult < 18 to 64 years> or aged <65+ years>) 	63	3

<i>Source</i>	<i>Search Strategy</i>	<i>Results</i>	<i>Hits</i>
Cinahl (EBSCOhost)	S1. Cognit* or memory S2. (MH*Neuropsychological Tests) S3. (MH*Down Syndrome) S4. (MH*Aging) S5. (MH*Age Factors) S6. S4 or S5 S7. S1 or S2 S8. S3 and S6 and S7 S9. Narrow by SubjectAge: - Aged: 65+ years; Middle Aged: 45-64 years; Adult: 19-44 years	29	1
PsycInfo (EBSCOhost)	S1. Cognit* or memory S2. MM*Neuropsychological Assessment S3. MM*Down's Syndrome S4. MM*Aging S5. DE*Age Differences S6. S4 or S5 S7. S1 or S2 S8. S3 and S6 and S7 S9. Narrow by SubjectAge: - Young Adulthood (18-29 yrs); Aged (65 yrs & older); Thirties (30-39 yrs); Middle Age (40-64 yrs); Adulthood (18 yrs & older)	56	2
ASSIA	Descriptors: "down's syndrome" AND (memory or cognit* or Neuropsychological Tests) AND (Ag*ing or Age Differences)	15	1
Google Scholar	down* syndrome (memory or cognit*) aging	19,000	0
Total		216	8

Table 2. Reference search of included articles

Reference Search	Article	Results	Hits
Web of Knowledge / Web of Science (1945-Week beginning July 2nd 2012) – Reference Search	Caltagirone et al. (1990)	4	0
	Carr (2003)	16	0
	Carr (2012)	0	0
	Das et al. (1995a)	16	0
	Das et al. (1995b)	21	0
	Devenny et al. 1992	18	0 (duplicates Carr, 2003; Krinsky-McHale et al. 2003)
	Devenny et al. (1996)	55	0 (duplicates – Carr, 2003; Krinsky-McHale et al. 2003)
	Krinsky-McHale et al. (2003)	8	0
	New Articles Found = 0		

Appendix 3: Quality criteria adapted from Scottish Intercollegiate Guidelines Network (SIGN)

Table 3. Checklist for assessing the quality of included studies. Adapted from SIGN Guidelines

Checklist Questions	Quality Criteria	
1. Study addresses an appropriate and clearly focussed question.	A. Question(s) appropriate and clearly focussed	Well covered (3)
	B. Question(s) appropriate and adequately focussed	Adequate (2)
	C. Question(s) inappropriate and poorly focussed	Poor (1)
	D. Question(s) not addressed, not reported or not applicable.	N/A (0)
2. Comparison / control group employed	A. Groups are well matched	Well covered (3)
	B. Groups are adequately matched	Adequate (2)
	C. Group are poorly matched	Poor (1)
	D. No comparison group, matching not reported	N/A (0)
3. The study employs reliable and validated neuropsychological test(s) of memory.	A. Test(s) employed have all demonstrated reliability and validity.	Well covered (3)
	B. Test(s) employed have demonstrated adequate reliability and validity.	Adequate (2)
	C. Test(s) employed have demonstrated poor reliability and validity.	Poor (1)
	D. Test(s) have not demonstrated reliability or validity.	N/A (0)
4. The study employs reliable and validated	A. All tests demonstrate reliability and validity.	Well covered (3)
	B. At least half of the tests employed have demonstrated	Adequate (2)

Checklist Questions	Quality Criteria	
neuropsychological tests of other cognitive functions.	reliability and validity.	
	C. Less than half of the tests have demonstrated reliability and validity.	Poor (1)
	D. None of the tests demonstrated reliability or validity.	N/A (0)
5. Tests were appropriate to the cognitive function being assessed.	A. Tests were very appropriate for cognitive function being assessed.	Well covered (3)
	B. Tests were adequate for cognitive function being assessed.	Adequate (2)
	C. Tests were poor for cognitive function being assessed.	Poor (1)
	D. Tests were inappropriate for cognitive function being assessed.	N/A (0)
6. Intellectual ability assessed using an appropriate standardised / validated measure.	A. Test was appropriate and demonstrated excellent reliability / validity.	Well covered (3)
	B. Test was appropriate and demonstrated adequate reliability / validity.	Adequate (2)
	C. Test was appropriate and demonstrated poor reliability / validity.	Poor (1)
	D. IQ test not addressed, not reported / not applicable.	N/A (0)
7. Presence of memory problems / dementia assessed and addressed at enrolment and throughout study.	A. Memory problems / dementia well assessed at enrolment and addressed throughout.	Well covered (3)
	B. Memory problems / dementia adequately assessed at enrolment and adequately addressed throughout.	Adequate (2)
	C. Memory problems / dementia poorly assessed at enrolment and poorly addressed	Poor (1)

Checklist Questions	Quality Criteria	
	throughout.	
	D. Memory problems / dementia not assessed at enrolment or addressed throughout.	N/A (0)
8. Other cognitive functions that could impact on memory taken into account in design and analysis.	A. Other cognitive functions well assessed.	Well covered (3)
	B. Other cognitive functions adequately assessed.	Adequate (2)
	C. Other cognitive functions poorly assessed.	Poor (1)
	D. Other cognitive functions not assessed.	N/A (0)
9. Study employs appropriate statistics and clearly reports these.	B. Statistics appropriate and clearly reported.	Well covered (3)
	C. Statistics appropriate and adequately reported.	Adequate (2)
	D. Statistics appropriate but poorly reported.	Poor (1)
	E. Statistics inappropriate, not clearly reported or not applicable.	N/A (0)
10. Effect sizes reported.	A. Effect sizes reported.	Yes (1)
	B. Effect sizes not reported.	No (0)
Total		(28)

Appendix 4: Summary of Quality Rating of Included Papers

Table 5. Quality rating of included papers

Criteria	<i>Das et al. (1995a)</i>	<i>Das et al. (1995b)</i>	<i>Krinsky-McHale (2003)</i>	<i>Caltagirone et al. (1990)</i>	<i>Carr (2003)</i>	<i>Carr (2012)</i>	<i>Devenny et al. (1996)</i>	<i>Devenny et al. (1992)</i>
1. Appropriate & clear question	3	3	3	1	1	0	0	2
2. Comparison / Control Group	1	1	2	1	0	0	1	1
3. Memory	2	2	2	1	2	2	1	1
4. Other tests of cognition	3	3	0	1	0	0	1	0
5. Appropriate tests	3	3	3	3	3	3	2	2
6. IQ Test	2	0	0	1	2	2	0	0
7. Dementia addressed	1	0	2	1	2	2	2	2
8. Other cognitive functions assessed	2	2	0	1	0	0	1	0
9. Statistics	3	3	3	3	3	3	2	1
10. Effect size	0	0	1	0	0	0	0	0
Total (28)	20	17	16	13	13	13	10	9

Table 5 shows individual scores on each quality criteria. Longitudinal papers received less points on quality overall (9-13) (Carr, 2003, 2012; Devenny et al., 1992, 1996) than cross-sectional papers (13-20) (Caltagirone et al., 1990; Das et al., 1995a, 1995b; Krinsky-McHale et al., 2003).

Appendix 5: Author guidelines, Journal of Intellectual Disability Research (JIDR)



SUBMISSION OF MANUSCRIPTS

Language: The language of publication is English. Authors for whom English is a second language must have their manuscript professionally edited by an English speaking person before submission to make sure the English is of high quality. It is preferred that manuscripts are professionally edited. A list of independent suppliers of editing services can be found at http://authorservices.wiley.com/bauthor/english_language.asp. All services are paid for and arranged by the author and use of one of these services does not guarantee acceptance or preference for publication.

Abbreviations, Symbols and Nomenclature: Spelling should conform to The Concise Oxford Dictionary of Current English and units of measurements, symbols and abbreviations with those in Units, Symbols and Abbreviations (1977) published and supplied by the Royal Society of Medicine, 1 Wimpole Street, London W1M 8AE. This specifies the use of SI units.

It is important that the term 'intellectual disabilities' is used when preparing manuscripts.

Please note that 'intellectual disability', as used in the Journal, includes those conditions labelled mental deficiency, mental handicap, learning disability and mental retardation in some countries.

Structure

All manuscripts submitted to *The Journal of Intellectual Disability Research* should include: Title, Keywords, structured Abstract, Main Text (divided by appropriate sub headings) and References.

Title Page: Please remember that **peer-review is double-blind**, so that neither authors nor reviewers know each others' identity. Therefore, **no identifying details of the authors or their institutions must appear in the submitted manuscript; author details should be entered as part of the online submission process**. However, a 'Title Page' must be submitted as part of the submission process as a 'Supplementary File Not for Review'. This should contain the title of the paper, names and qualifications of all authors, their affiliations and full mailing address, including e-mail addresses and fax and telephone numbers.

Keywords: The author should also provide up to six keywords to aid indexing.

Abstracts: For full and brief reports a structured summary should be included at the beginning of each article, incorporating the following headings: **Background, Method, Results, and Conclusions.** These should outline the questions investigated, the design, essential findings, and the main conclusions of the study.

Optimizing Your Abstract for Search Engines: Many students and researchers looking for information online will use search engines such as Google, Yahoo or similar. By optimizing your article for search engines, you will increase the chance of someone finding it. This in turn will make it more likely to be viewed and/or cited in another work. We have compiled these guidelines to enable you to maximize the web-friendliness of the most public part of your article.

References

The Journal follows the Harvard reference style. References in text with more than two authors should be abbreviated to (Brown et al. 1977). Authors are responsible for the accuracy of their references.

The reference list should be in alphabetical order thus:

- Giblett E.R. (1969) Genetic Markers in Human Blood. Blackwell Scientific Publications, Oxford.
- Moss T.J. & Austin G.E. (1980) Preatherosclerotic lesions in Down's syndrome. *Journal of Mental Deficiency Research* **24**, 137- 41.
- Seltzer M. M. & Krauss M.W. (1994) Aging parents with co-resident adult children: the impact of lifelong caregiving. In: *Life Course Perspectives on Adulthood and Old Age* (eds M. M. Seltzer, M.W. Krauss & M. P. Janicki), pp. 3-18. American Association on Mental Retardation, Washington, DC.

Where more than six authors are listed for a reference please use the first six then 'et al.'

The Editor and Publisher recommend that citation of online published papers and other material should be done via a DOI (digital object identifier), which all reputable online published material should have - see www.doi.org/ for more information. If an author cites anything which does not have a DOI they run the risk of the cited material not being traceable.

We recommend the use of a tool such as EndNote or Reference Manager for reference management and formatting.

EndNote reference styles can be searched for here: www.endnote.com/support/enstyles.asp

Reference Manager reference styles can be searched for here:
www.refman.com/support/rmstyles.asp

Tables, Figures and Figure Legends

Tables: Tables should include only essential data. Each table must be typewritten on a separate sheet and should be numbered consecutively with Arabic numerals, e.g. Table 1,

Table 2, etc., and given a short caption.

Figures: All graphs, drawings and photographs are considered figures and should be numbered in sequence with Arabic numerals. All symbols and abbreviations should be clearly explained.

Tables and figures should be referred to in the text together with an indication of their approximate position recorded in the text margin.

Preparation of Electronic Figures for Publication

Although low quality images are adequate for review purposes, print publication requires high quality images to prevent the final product being blurred or fuzzy. Submit EPS (line art) or TIFF (halftone/photographs) files only. MS PowerPoint and Word Graphics are unsuitable for printed pictures. Do not use pixel-oriented programmes. Scans (TIFF only) should have a resolution of at least 300 dpi (halftone) or 600 to 1200 dpi (line drawings) in relation to the reproduction size (see below). Please submit the data for figures in black and white or submit a Colour Work Agreement Form (see Colour Charges below). EPS files should be saved with fonts embedded (and with a TIFF preview if possible).

For scanned images, the scanning resolution (at final image size) should be as follows to ensure good reproduction: line art: >600 dpi; halftones (including gel photographs): >300 dpi; figures containing both halftone and line images: >600 dpi.

Further information can be obtained at Wiley-Blackwell's guidelines for figures:
<http://authorservices.wiley.com/bauthor/illustration.asp>

Check your electronic artwork before submitting it:
<http://authorservices.wiley.com/bauthor/eacchecklist.asp>

Permissions: If all or parts of previously published illustrations are used, permission must be obtained from the copyright holder concerned. It is the author's responsibility to obtain these in writing and provide copies to the Publisher.

Colour Charges: It is the policy of *The Journal of Intellectual Disability Research* for authors to pay the full cost for the reproduction of their colour artwork. Therefore, please note that if there is colour artwork in your manuscript when it is accepted for publication,

Wiley-Blackwell require you to complete and return a Colour Work Agreement Form before your paper can be published. Any article received by Wiley-Blackwell with colour work will not be published until the form has been returned. If you are unable to access the internet, or are unable to download the form, please contact the Production Editor (jir@wiley.com)

Figure Legends: In the full-text online edition of the Journal, figure.

Appendix 6: Ethical approval: Scotland A Research Ethics Committee

Scotland A Research Ethics Committee

Secretariat
2nd Floor Waverley Gate
2-4 Waterloo Place
Edinburgh
EH1 3EG
Telephone: 0131 465 5680
Fax: 0131 465 5789
www.nres.nhs.uk



Miss Ann McPaul
Trainee Clinical Psychologist
NHS Highland
New Craigs Hospital
Drumossie Unit
Leachkin Road
Inverness
IV3 8NP

Date: 29 February 2012
Your Ref.:
Our Ref.: 12/SS/0020
Enquiries to: Walter Hunter
Extension: 35680
Direct Line: 0131 465 5680
Email: walter.hunter@nhslothian.scot.nhs.uk

Dear Miss McPaul

Study title: The clinical utility of the Visual Association Test (VAT) in adults with intellectual disabilities

REC reference: 12/SS/0020

Thank you for your e-mails dated 28 and 29 February 2012. I can confirm the Scotland A REC has received the documents listed below as evidence of compliance with the approval conditions detailed in our letter dated 23 February 2012. Please note these documents are for information only and have not been reviewed by the Committee.

Documents received

The documents received were as follows:

Document	Version	Date
Participant Consent Form: Participant	1	30 January 2012
Participant Information Sheet: Participant	2	28 February 2012
Participant Information Sheet: Optional Information Booklet		February 2012
Participant Information Sheet: Staff	3	29 February 2012

You should ensure that the version number and date on each document is consistent as per the version number and dates above i.e. there is an inconsistency in the participant and staff information sheets on different pages. There is also a typographical error on the second page of the staff information sheet i.e. 'Dr Alan Johnes'.

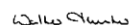
Chairman Dr Ian Zealley
Vice-Chairman Dr Colin Selby



You should also ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

REC reference number: 12/SS/0024-Please quote this number on all correspondence

Yours sincerely

A handwritten signature in cursive script, appearing to read 'Walter Hunter'.

WALTER HUNTER
Committee Co-ordinator
cc: Dr Lynn Morrice
Dr Frances Hines, NHS Highland



Appendix 7: Research and Development Approval, NHS Highland

Professor Angus Watson
Research & Development Director
NHS Highland Research & Development Office
Room S101
Centre for Health Science
Old Perth Road
Inverness
IV2 3JH

Tel: 01463 255822
Fax: 01463 255838
E-mail: angus.watson@nhs.net



16 March 2012

NHS Highland R&D ID: **822**
NRSPCC: **NRS12/CG08**

Miss Ann McPaul
Trainee Clinical Psychologist
New Craigs Hospital
Drumossie Unit
Leachkin Road
Inverness
IV3 8NP

RECEIVED

Dear Miss McPaul,

Management Approval for Non-Commercial Research

I am pleased to tell you that you now have Management Approval for the research project entitled: **'The Clinical Utility of the Visual Association Test (VAT) in Adults With Intellectual Disabilities'**. I acknowledge that:

- The project is sponsored by the University of Edinburgh.
- The project does not require external funding.
- Research Ethics approval for the project has been obtained from the Scotland A Research Ethics Committee, (Reference Number: 12/SS/0020).
- The Site-Specific Information form for this site has been reviewed (completed on date 09/03/12) and there is no objection to NHS Highland being included as a site for this project

Headquarters:
NHS Highland, Assynt House, Beechwood Park, Inverness, IV2 3HG

Chairman: Mr Garry Coutts
Chief Executive: Elaine Mead
Highland NHS Board is the common name of Highland Health Board

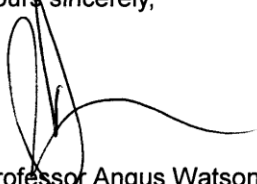


The following conditions apply:

- The responsibility for monitoring and auditing this project lies with the University of Edinburgh.
- This study will be subject to ongoing monitoring for Research Governance purposes and may be audited to ensure compliance with the Research Governance Framework for Health and Community Care in Scotland (2006, 2nd Edition), however prior written notice of audit will be given.
- All amendments (minor or substantial) to the protocol or to the REC application should be copied to the NHS Highland Research and Development Office together with a copy of the corresponding approval letter.
- The paperwork concerning all incidents, adverse events and serious adverse events, thought to be attributable to participant's involvement in this project should be copied to the NHS Highland R&D Office.
- Monthly recruitment rates should be notified to the NHS Highland Research and Development Office, detailing date of recruitment and the participant trial ID number. This should be done by e-mail on the first week of the following month.

Please report the information detailed above, or any other changes in resources used, or staff involved in the project, to the NHS Highland Research and Development Manager, Frances Hines (01463 255822, frances.hines@nhs.net).




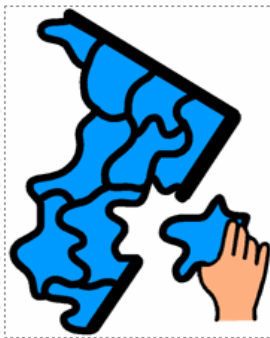
Yours sincerely,

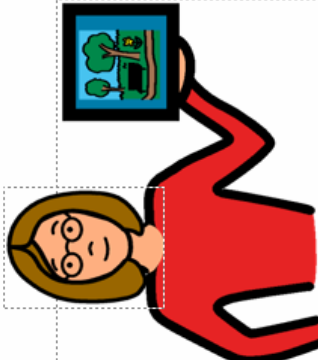
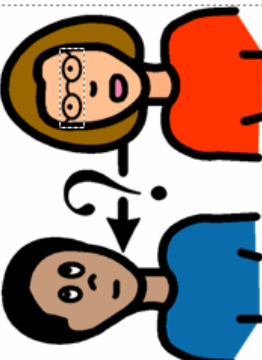
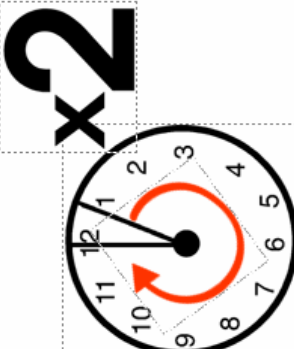








Professor Angus Watson
NHS Highland Research and Development Director

cc Frances Hines, R&D Manager, NHS Highland Research & Development Office,
Room S101, The Centre for Health Science, Old Perth Road, Inverness, IV2 3JH
Pamela Shand, Senior Administrator, NHS Research Scotland Coordinating Centre,
Research & Development Office, Foresterhill House Annexe, Foresterhill,
Aberdeen, AB25 2ZB

Appendix 8: Participant easy-read booklet

 <h1>Research study</h1> 	<p>What the study is about.</p> <p>The University of Edinburgh would like your help.</p> <p>We are doing a study looking at a memory test.</p> <p>We are doing this to see if the test can be used to help people with learning disabilities.</p> <p>If you would like to help us we will ask you to do some tasks.</p> <p>XXX XXXX, Trainee Clinical Psychologist, will do these tasks with you.</p> <p>The tasks:</p> <p>XXX will ask you to do some puzzles.</p>
<p>If you want to find out more XXX will come and speak to you.</p> <p>You can also speak to XXXX XXXX, Consultant Psychologist, to find out more.</p> <p>Please tick one box to say what you want to do.</p> <p>Yes, I am happy to meet XXX to find out more.</p> <p>No, I do not want to take part.</p> <p>Photo of independent contact</p> <p>Contact us on:</p> <p>Psychology Department (Learning Disabilities) Drumossie Unit New Craigs Hospital Leachkin Road Inverness, IV3 8NP Telephone: 01463 253697</p> <p><small>Produced by XXX XXXXXXX, Trainee Clinical Psychologist & Accessible Information Officer, Version 2 February 2012 PCS / Beardmaker1981 - 2012 by Mayer-Johnson LLC. Used with permission. www.mayer-johnson.com</small></p>	 <p>Researchers photo</p> 

	<p>XXX will show you photos</p>
	<p>XXX will ask you questions.</p>
	<p>The tasks may take up to 2 hours to do.</p> <p>You can take breaks when you are doing the tasks.</p>
	<p>XXX will meet you a clinic that is near to you or at your home.</p>
	<p>You can meet XXX more than once to do the tasks.</p>
	<p>Taking part is voluntary. That means it is up to you.</p>
	<p>You can say Yes if you want to take part.</p>
	<p>You can say No if you do NOT want to take part.</p>
	<p>It is ok if you say No. This will not affect any other work you do with any other staff.</p>

Appendix 9: Participant information sheet



MEMORY AND LEARNING DISABILITIES

PARTICIPANT INFORMATION SHEET

We would like to invite you to take part in a research study. The aim of the study is to find better ways to assess people's memory. The information sheet tells you about the study. Please read the information sheet, or ask someone to read it with you. This information sheet is for you to keep.

You can talk to your family and friends about the study. Ask them what they think about it.

What is the research study about?

The aim is to see if we can assess memory using a tool called the Visual Association Test (VAT).

The VAT is helpful in assessing memory in adults and in older people. We want to see if the VAT is helpful for assessing memory in people with a learning disability.

Having good tests for memory can help us tell if there are any problems we can help with.

Our memory helps us to remember:

- people's names
- names of objects
- things that we have done in the past

Why do you want me to take part?

We are inviting you to take part because you are using the learning disabilities services. A staff member who knows you thinks you might be interested in taking part.

What will the research study involve?

If you want to find out more the researcher will contact you and ask to visit you. You do not have to meet the researcher. The researcher is a Trainee Clinical Psychologist and will be supervised by a qualified Clinical Psychologist.

You can ask the researcher questions about the study. The researcher will ask you to decide if you want to take part in the research study. If you say yes, you will be asked to sign a consent form. You can keep a copy of the form.

If you choose to take part, the researcher will visit you again. The meetings will be at a place that is suitable for you. The appointments will last between one and two hours.

The researcher will do some tests with you. This will involve showing you pictures of objects and asking you to name them. The researcher may ask you to do other tasks and ask questions about words and numbers.

We would like to look at your medical file to check if you have any physical problems which may affect your memory. We would also like to look at your psychology file to see if you have completed any of these tests before.

We will ask you if we can tell your GP that you are taking part in the study.

What if there is a problem?

If you have a concern about the study, you should ask to speak to the researcher. The researcher will do their best to answer your questions. If you would like to speak to someone else about this study you can call NAME, TELEPHONE NUMBER.

If you wish to complain about any aspect of the way you have been treated during the course of this study, the normal National Health Service complaints mechanism will still be available to you.

Has ethical approval been granted for this study?

This study has been granted ethical approval by the Scotland A Research Ethics Committee.

When will the study take place?

This study will take place during 2012. You will meet the researcher on a maximum of three appointments.

Will taking part in the study help me?

Taking part might not help you directly. Nobody has used this test before with people with learning disabilities.

The results of this study may help us in the future to test other people's memory.

What will happen if I decide not to take part in the study?

You do not have to take part in this research study. It is OK to say no. If you don't want to take part, this will not affect the care and support you receive.

What if I change my mind and do not want to take part during the study?

You can change your mind about taking part, or stop, at any time. You do not have to give a reason. If you change your mind this will not affect the care and support you receive.

Where would the interviews take place?

If it is OK with you, the researcher will arrange to see you at either your home or at a clinic if you prefer. If you want the researcher can arrange to see you somewhere else.

What will happen to the information the researcher collects?

All the information about you is kept safe. It will be treated with strict confidence. It will be kept secret. The researcher will not tell anyone your name. The information will be kept safely on a computer. The Data Protection Act will be followed at all times.

What will happen to the results of the study?

When the research study is finished, the researcher will write to you about the research findings. They will also write reports about the research. Your name will not be used in the reports. No one will be able to tell from the reports if you took part in the research.

Who is organising and funding the research?

This study is part of the researcher's Doctorate in Clinical Psychology qualification. The money to pay for the study was provided by the University of Edinburgh.

How can I find out more about the study?

You can ask the researcher questions about the study. The name and telephone number of the researcher is shown below. You can contact her at any time to ask questions.

You might like to speak to someone else about the research. NAME SURNAME can be contacted on the telephone. His number is XXXXX. NAME will try and answer any questions you have.

Thank you for reading this information sheet.

Researcher
NAME
ADDRESS
RELEPHONE

**What do I do now?**

It is up to you to choose whether you want to take part in the study. Let us know if you want to find out more about the study by ticking one of the boxes.

If you tick the **YES** box the researcher will contact you.

YES

☐

If you tick the **NO** box the researcher will not contact you.

NO

☐

If yes, please fill in your contact details

NAME.....

Address.....

.....

.....

.....

Telephone Number.....

Appendix 10: Staff information sheet



ADDRESS
POSTCODE
TELEPHONE NUMBER
EMAIL

NHS LOGO

Date

Staff Information Sheet

Study Title: The clinical utility of the Visual Association Test (VAT) in adults with Intellectual Disabilities

Your patient is being invited to take part in a research study. It is important for you to understand why the research is being carried out and what it will involve.

Why are we doing this research?

This research project is examining the utility of the Visual Association Test (VAT) in adults with intellectual disabilities. The VAT is a neuropsychological test of associative memory. The project is hoping to find out how adults with intellectual disabilities perform on this test and whether it could be used as a clinical tool in the future.

Why have they been invited to take part?

Your patient has been invited to take part as they have an intellectual disability. The study aims to include 44 people between 18 and 45 years of age.

Do they have to take part?

It is up to the person whether they consent to taking part. If they decide to take part they are free to change their mind at any time during the study without giving a reason. A decision to withdraw from the study or not to take part will not affect their standard of care.

What is involved?

Your patient will be seen by Ann McPaul, Trainee Clinical Psychologist to assess whether they have the capacity to consent to the research. If they can consent and do wish to take part, Ann will arrange to see them again at an agreed time at their home or at a clinic nearby. The patient will be asked to complete some assessments of their memory and cognitive abilities. This may take between one to two hours to complete, breaks will be provided and the assessment may be completed over one or two sessions.

Is there any harm to participating in this research?

The tasks and assessments used in this study will not cause them any harm. However, if you were to have any concerns, Ann McPaul would discuss these with you.

How is this research useful?

Taking part does not have direct benefits or disadvantages. However, the information we get from this study may help us to learn more about the utility of this test in assessing memory in people with intellectual disabilities. In the long-term, this may help us in screening for dementia in people with intellectual disabilities.

What if there is a problem?

If you have a concern about any aspect of the study, you should ask to speak to Ann McPaul, who will do her best to answer your questions. If you would like to speak to an independent person about this study you may also contact NAME, DESIGNATION, TELEPHONE NUMBER who will answer any queries you may have relating to this research.

If you wish to complain formally regarding your treatment during your participation in the research, you can do this through the organisations Complaints Procedure. Details of this can be obtained from the hospital. The normal National Health Service complaints mechanism will still be available to you.

What will happen to the results of the research study?

Your patient can choose to have a summary of the results emailed or posted to them after the end of the study in August 2012. The results of this study may be published in a scientific journal and if so, will be published one to two years after the end of the study. It will not be possible to identify participants in any of these reports.

Will my taking part in this research be kept confidential?

All information which is collected about the patient during the course of the research will be kept strictly confidential. Only members of the research team will have access to this information. Any information about your patient will have their name and address removed so that they cannot be recognised from it.

With their permission we will inform their General Practitioner of their participation in this study. In the unlikely event that participation uncovers a problem, we will also seek their permission to inform their GP.

We will also ask their permission to access their medical file for further information about any medical conditions which may impact on testing. In addition, we will ask for permission to access their psychology file to see if they have completed a WAIS-IV assessment and if so, this will not be repeated.

Who is organising and funding the research?

This study is part of the researcher's Doctorate in Clinical Psychology qualification. This research is being funded by the University of Edinburgh.

Who has reviewed the study?

All research is looked at by an independent group of people, called a Research Ethics Committee to protect your patient's safety, rights, wellbeing and dignity. This research has been reviewed by an NHS ethics committee.

Who do I contact for further information?

If you would like any more information about this study, please contact Ann McPaul (Trainee Clinical Psychologist) on XXXX. Alternatively, if you would like to speak to an independent person about this study, please contact NAME, DESIGNATION, TELEPHONE NUMBER.

Thank you for reading this information sheet.

Appendix 11: Participant consent form



MEMORY AND LEARNING DISABILITIES

PARTICIPANT CONSENT FORM

This form asks if I will take part in a research study.

A researcher will ask me questions about my memory.

The researcher will keep my information confidential (secret) and safe.

Please tick the box if you agree with what it says.

I have been given an information sheet about the study	YES	<input type="checkbox"/>
I have asked all the questions I want to	YES	<input type="checkbox"/>
I have been given enough answers to my questions.	YES	<input type="checkbox"/>
I know it is OK to say 'No' to taking part in the study. I don't have to take part. I don't have to say why.	YES	<input type="checkbox"/>
Saying 'No' will not affect my care or support in any way.	YES	<input type="checkbox"/>
I know I can change my mind and say 'No' later on.	YES	<input type="checkbox"/>
I know the researcher will write about the study results.	YES	<input type="checkbox"/>
I know the results will not include my name. No one will be able to identify me from the results.	YES	<input type="checkbox"/>
The researcher will let my GP know I am taking part.	YES	<input type="checkbox"/>
I consent to my medical and psychology file being accessed for further information.	YES	<input type="checkbox"/>

I know that relevant sections of my medical notes and data collected in this study may be looked at by the regulatory authorities, sponser or NHS organisation.

YES

☐

I agree to taking part in the research study

YES

☐

Participant signature of consent

Signed

Name

Date

Witness signature

Signed.....

Name

Date

Researcher

NAME
ADDRESS
TELEPHONE

Researcher's
Photo

Researcher signature

Signed.....

Name.....

Date